The Health Committee

The Health Committee is appointed by the House of Commons to examine the expenditure, administration, and policy of the Department of Health and its associated bodies.

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Publications

The Reports and evidence of the Committee are published by The Stationery Office by Order of the House. All publications of the Committee (including press notices) are on the Internet at www.parliament.uk/healthcom

Committee staff

The current staff of the Committee are Dr David Harrison (Clerk), Emma Graham (Second Clerk), Christine Kirkpatrick (Committee Specialist), Ralph Coulbeck (Committee Specialist), Duma Langton (Committee Assistant), Julie Storey (Secretary), Jim Hudson (Senior Office Clerk) and Luke Robinson (Media Adviser).

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Written evidence

Evidence submitted by the Department of Health (PPI 1)

1. This evidence addresses the terms of reference set out by the Committee. Additional information can be found in:
   - Part 11 of the Local Government and Public Involvement in Health Bill published in December 2006;
   - A Stronger Local Voice published by the Department of Health in July 2006; and
   - The Government response to A Stronger Local Voice published by the Department of Health in December 2006.

What is the purpose of patient and public involvement?

2. We believe that the ultimate purpose of user and public involvement is the production of improved services, which better satisfy the needs and wants of users of services. Patients, carers and users of services are experts in the care they need and want their input is therefore essential if services are to be tailored to their needs, to create a patient led NHS. We also feel that it is essential to involve users, as well as the groups that represent them, in the commissioning decisions that are taken, to ensure they have input into what services are provided in any locality. This will create local ownership and support for services.

3. Patient and user involvement also assists in the scrutiny of services through representing people’s views, and allowing users a route to assuring the quality of the services they use.

What form of patient and public involvement is desirable, practical and offers good value for money?

4. The system of user and public involvement should involve as many people as possible. During the consultation leading up to the publication of the White Paper Our health, our care, our say: a new direction for community services we heard that more people want to have a greater say about their local services. Our consultation also showed that people want to be involved in different ways—some having a large amount of time to dedicate, others wishing to dip in and out of involvement. The system of user and public involvement must accommodate different ways of getting involved, to give a large and diverse number of people a means of influencing the services commissioned and provided in their area.

5. The system of user involvement can also offer good value for money by ensuring that the greatest possible proportion of the funds available are spent on front line engagement work rather than on central structures to support user involvement. Currently approximately £9 million is spent annually on supporting CPPHI, which represents 32% of the total PPI budget. The costs of Local Authorities administering and monitoring contracts with host organisations will vary according to the nature of their area and each Local Authority’s infrastructure. However, it is estimated that Local Authorities will need between £5,000 and £15,000 for this work. It is our expectation that the same amount of funding will go to the new system as is currently spent on PPI, therefore, even if each Local Authority is at the higher end of the scale, their expenditure represents roughly 8% of the total budget. We believe it is beneficial to redirect funds towards frontline engagement work.

Why are existing systems for patient and public involvement being reformed after only three years?

The Department of Health’s Arm’s Length Bodies Review announced the abolition of the Commission for Patient and Public Involvement in Health in July 2004. The decision supported a wider agenda set by the review to reduce bureaucracy and free up more resources for the frontline.

Following this announcement and the publication of Commissioning a Patient Led NHS and the proposed reconfiguration of PCTs, Ministers announced a strategic review of the PPI system as they recognised that the nature of health and social care delivery is changing radically, for example:

- PCTs’ changing role to focus on the commissioning of services;
- the role of commissioning as the means through which services are managed, controlled and developed;
- the move towards greater choice of service providers and service delivery;
- the increased focus within social care on choice and control with more emphasis on personalisation of services, self-directed support, and the use of direct payments;
— the move towards the integration of health and social care, the delivery of more services within the community; and
— the emergence of NHS Foundation Trusts, as well as many other providers from the independent sector.

6. PCTs and other commissioners are the power base of the new NHS, with 80% of budgets being devolved to them. In the future there will be an increasing mix of providers, meaning that the old system of user involvement, that was focussed around individual NHS institutions is no longer appropriate.

7. We want to build on the excellent work of PPI Forums and other methods of service user and public involvement, to create a new system that is clear and accessible. It should provide more people, young and old, from a wide diversity of backgrounds and needs, with the opportunity to influence public services in ways that are relevant and meaningful to them.

**How should LINks be designed, including:**

**Remit and level of independence**

8. We believe that LINks should cover both health and social care. Currently the system of focusing user involvement around Forums established for each NHS Trust means that often services are considered in isolation. LINks will be able to cover all services in their area, looking at those jointly commissioned between health and social care, and gathering comments on all aspects of user experience.

9. LINks should be independent of external control, so that they are able to make their own decisions about what issues to consider, and make recommendations based on the comments they hear. We are eager that LINks are described in a minimum of detail in legislation so that they are free to be flexible to local circumstances, rather than being centrally prescribed.

10. Local Authorities will be required to procure a host organisation which will support the LINk, however, they will not have control over the LINk's actions, or how the LINk spends its funds, this should ensure the LINk is free from political control.

**Membership and appointments**

11. We think that membership of LINks should be locally determined by each LINk structure. We do not wish to prescribe a central governance structure and form that the LINk should take, We will offer some models that the LINk could choose to follow, but its membership and structure will be free to follow whatever form is most appropriate locally.

12. It is important to note that the term “membership of a LINk” may be misleading. It will be possible, and indeed sometimes desirable, for people to feed their views and experiences into a LINk without seeing themselves as “members”. By making a complaint, or filling in a comment card or talking to a PALS officer, an individual is contributing to the evidence-base collected by the LINk. Similarly, LINks may want to have their own web sites to which people will be invited to visit and log their thoughts, ideas and experiences. The key issue is that LINks are able to reach out to and hear from as wide a range of people as possible rather than relying on the views of a small group of heavily “involved” people.

**Funding and support**

13. Money will be given to every upper tier local authority which will be required to contract with a local organisation such as a voluntary and community group host LINk. The host organisation will hold the funds of the LINk, and will spend them as instructed by the LINk’s governance structure. The host will provide administrative and organisational support to the LINk.

14. We believe that subject to normal budgetary pressures, the new system should receive the same level of funding as is currently available to the Commission for Patient and Public Involvement in Health (CPPIH) and patient forums. The Government is currently involved in a Comprehensive Spending Review which will set spending 2008–09 to 2010–11. We expect the results of this review to be published in the summer.

**Areas of focus**

15. We believe that LINks should have the power to determine what areas of work they focus on, within their statutory functions which will be:

— promoting and supporting the involvement of people in the commissioning, provision and scrutiny of local care services;
— obtaining the views of people about their needs and experiences of local services;
— making the views they gather known to commissioners and providers of services, and making reports and recommendations to those taking decisions about these services.
16. We believe that the LINk, directed by its governance structure, and the decision making process it has put in place, should have the power to focus on issues which it has heard are of concern to the local community.

Statutory powers

17. LINks will have similar powers to patients’ forums, these include the power to:
   - enter and assess health and social care facilities;
   - make reports and recommendations and receive a response within a specified timescale;
   - request information and receive a response within a specified timescale; and
   - refer matters to an Overview and Scrutiny Committee and receive an appropriate response.

18. To enable LINks to gather information from all types of patients and users of services, there will be times when it is right to collect peoples’ experiences whilst they are currently using services. We therefore plan to provide LINks with the power to enter health and social care premises (with some exceptions) and to observe and assess the nature and quality of services.

19. LINks will not have the right to enter all premises, for example they will not have the right to enter social care facilities which provide services for children. Not all members of LINks will undertake this role, indeed some members will not want to undertake this type of activity, and that will be acceptable. Those who are able to exercise the right need to:
   - have appropriate skills;
   - have received appropriate training;
   - be cleared by the Criminal Records Bureau; and
   - be able to demonstrate an understanding of patient confidentiality and an appropriate level of sensitivity towards the role.

Relations with local health Trusts

20. We intend LINks to be flexible, and able to be adapted to best fit local circumstances. Therefore, whilst we are not prescribing their structure or make up, we imagine that a LINk may well wish to set up specialist interest groups, for example, one that considers mental health services within its area, or relates to a particular hospital trust. LINks may wish to work together in considering services which span local authority boundaries.

21. We hope that LINks will create strong working relationships with the Trusts in their area, and build on the partnerships that have already been created by patients forums and local voluntary and community sector organisations. LINks will have powers to request information from trusts, as well as enter and assess their premises, these should help them in close scrutiny, and close working with these trusts.

National coordination

22. Whilst LINks are independent and will have the power to develop their own priorities and agendas, they will need to develop relationships with a number of stakeholders to fulfil their statutory role effectively. In certain circumstances LINks may want to work in partnership to scrutinise services across local authority boundaries. LINks may also wish to work together in regional groups, or even nationally to share experience and findings. We believe there is nothing to prevent LINks establishing a national body to share and coordinate their work if they so wish.

How should LINks relate to and avoid overlap with:

Local Authority structures including Overview and Scrutiny Committees

23. We envisage that LINks will have a close and mutually beneficial relationship with OSCs. LINks will have the power to refer matters of concern to the OSC and the right to receive a response. OSCs may well find LINks’ recommendations useful in raising issues, with a large evidence base behind them, which many people have found to be of concern. This close relationship should not prejudice the independence of either party, as they remain separate organisations with their own decision making capability.
Foundation Trust boards and Members Councils

24. It may well be that many of the members of a LINk are also members of Foundation Trusts. It will be up to the LINk's governance structure and organisational rules to ensure that there are no conflicts of interest, and to manage any such problems. Foundation Trusts also have duties to seek the views of the whole community, therefore they may be very interested in the research and recommendations of the LINk. In addition, the Foundation Trust may share its findings with the LINk, and it is possible that they would do joint pieces of work together.

Inspectorates including the Healthcare Commission

25. It is our intention to set out in secondary legislation the requirements for LINks to co-operate with the regulators in relations to the LINks' functions of entering and assessing premises. This will ensure that LINks will co-ordinate their work to ensure that this does not conflict with, or duplicate the work of the inspectors.

26. We are clear that LINks are not an “inspectorate”—they have the power to enter and view premises, and observe services. This should be undertaken when there is an evidence base of comments they have received to indicate that there is cause for concern with a certain service. This power will also assist LINks in gathering the views of people whilst they are actually receiving services.

27. LINks will also have a role in contributing to the annual assessment process of the regulators.

Formal and informal complaints procedures

28. LINks will not have a role to deal with advocacy or complaints. This is the role of the Independent Complaints and Advocacy Service (ICAS) and Patients Advice and Liaison Services (PALS), who will continue to successfully deal with formal and informal complaints procedures.

29. However, LINks will often wish to use the data collected by these organisations to help them gather and access people’s views of services. LINks' powers to request information will assist them in gathering this type of information, for example, in asking an NHS Trust how many complaints it has had on a certain issue.

In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

30. Section 11 places a duty on the NHS to involve and consult patients and the public:
   — not just when a major change is proposed, but in the ongoing planning of services;
   — not just when considering a proposal but in developing that proposal; and
   — in decisions that may affect the operation of services.

31. “Involving and consulting” has a particular meaning in the context of Section 11. It means discussing with patients and the public their ideas, their experiences, the plans being proposed, why services need to change, what they want from services, how to make the best use of resources and so on. It is more about changing attitudes within the NHS and the way the NHS works than laying down rules for procedures. We will simplify, clarify and strengthen the current legislation on health service consultation.

32. We intend to give PCTs a new statutory duty to respond to local people, explaining the activities they are undertaking as a result of what people have said throughout the year. There will be a structured process whereby commissioners will publish regular reports of what they have done differently as a result of what they have heard and say why they might not have taken forward some suggestions. The process will be open and there will be transparent communication to develop trust and confidence and increase accountability to local people.

33. A LINk or an OSC may decide to review how local commissioners are communicating with the public and make recommendations for improvement.

Department of Health
5 January 2007

Evidence submitted by Action against Medical Accidents (PPI 40)

1. Summary

This memorandum sets out the views of the charity Action against Medical Accidents (AvMA) on the issues around Patient & Public Involvement in Health (PPI) under consideration by the Committee. In particular, AvMA expresses its concerns about:
— Independent Complaints Advocacy Services (ICAS) not being delivered in accordance with the legislation which established the new system of PPI to replace Community Health Councils (CHCs), and not being integrated with the new PPI structures such as Patients Forums (now referred to as “Patient & Public Involvement Forums” (PPIFs), and LINks, as proposed by the Government.

— The proposed methods of providing staff support to the new LINks; the appointment of members; and the absence of a statutory right to inspect NHS organisations. AvMA believes the proposed arrangements for LINks fail to take on board the lessons and experience from CHCs and PPIFs, and would lead to LINks failing to be effective or enjoy public confidence.

2. ABOUT ACTION AGAINST MEDICAL ACCIDENTS (AVMA) AND THE AUTHOR OF THIS MEMORANDUM, PETER WALSH

2.1 Action against Medical Accidents (AvMA) is a patient centred charity with considerable experience, now stretching back 25 years, of working with local and national bodies providing patient and public involvement in the NHS. This included close working with CHCs and ACHCEW before their abolition, as well as the current system of CPHIH, Patients Forums and ICAS. The arrangements for patient and public involvement have a real impact on the beneficiaries of the charity and our own work. We are able to draw on considerable experience of what works best and what is needed.

2.2 The author of this memorandum, Peter Walsh, is chief executive of AvMA. Prior to his appointment in January 2003 he was the Director of the Association of Community Health Councils in England & Wales (ACHCEW) and chief officer of a local CHC. As Director of ACHCEW he was closely involved in the development of plans for the new system of PPI and the legislation leading to its establishment and the abolition of CHCs through work with the Transition Advisory Board, with Department of Health officials and Ministers.

3. INDEPENDENT COMPLAINTS ADVOCACY SERVICE (ICAS)

3.1 AvMA is very disappointed that ICAS has been given scant attention in the new vision for patient and public involvement. The complaints support function of CHCs was a highly valued part of their role, and in the debates leading to the establishment of the new system ministers gave assurances that ICAS would be an integral part of the role of Patients Forums, with ICAS being delivered by staff of PCT patients forums. This would have safeguarded the availability of a local “one stop shop” for patients and the public. There has been strong consensus on the need for this kind of integration. The NHS Reform & Healthcare Professions Act 2002 made it a function of PCT Patients Forums to provide ICAS:

16 Additional functions of PCT Patients’ Forums

(1) A Patients’ Forum established for a Primary Care Trust (a “PCT Patients’ Forum”) has the following additional functions:

(a) providing independent advocacy services to persons in the Trust’s area or persons to whom services have been provided by, or under arrangements with, the Trust; and

(b) making available to patients and their carers advice and information about the making of complaints in relation to services provided by or under arrangements with the Trust, and NHS Reform & Healthcare Professions Act 2002.

3.2 AvMA believes that the failure to implement this part of the Act has been detrimental to the ICAS service itself and the system of local patient and public involvement. There is no identifiable “one stop shop” where patients and the public can go to get independent support with complaints or concerns or get involved with local health matters. Patients Forums are not benefiting from timely, detailed information about issues gleaned from complaints and do not have their own staff.

3.3 AvMA, given its focus on patient safety, is concerned that the lack of integration between ICAS and the monitoring role of patients forums (or LINks in the future) will weaken the potential of both to recognise potential problems and make interventions to reduce risks to patients.

3.4 It was always accepted (both in the debates about abolition of CHCs and in the multi-agency work of the Transition Advisory Board) that ICAS needed to be completely independent of the NHS and of the Department of Health. However, ICAS continues to be controlled and directly commissioned by the Department of Health even though its delivery is via three voluntary organisations. Five year contracts have been awarded to these organisations despite the fact the legislation stipulates ICAS should be provided by PCT Patients Forums.
3.5 ICAS is also being provided in an inconsistent way across the country by three quite different providers who are not formally linked in any way to patients forums. There has been no independent evaluation of the current arrangements for ICAS.

3.6 We recommend that the opportunity is taken in developing LINks to integrate with them the provision of ICAS by providing them with the staff to deliver ICAS through an easily identifiable, local one stop shop. This would have the benefits of:

— ensuring that the monitoring work of the LINks is informed by intelligence from complaints about various NHS providers in their “patch”; and

— providing economies of scale and helping with recruitment and retention of staff.

Although CHCs were under-resourced, the fact that their complaints support function as well as the administrative/management support for the organisation were provided by their own staff meant that they did not have to rely solely on externally provided data on complaints (which without fuller context is not that useful anyway). It also meant that staff working with CHCs were able to multi-task and support each other in the various tasks. This made them more efficient and cost-effective than the current unwieldy and costly system where the functions have been split up and hived off.

4. LINks

4.1 AvMA has a number of concerns about the way that LINks are currently envisaged. Whilst we agree with the importance of focussing on commissioning and taking a strategic view on behalf of local communities, we disagree with the abandonment of monitoring services. One of the strengths of CHCs was that they combined these functions. The understanding of the nature of services and patients’ experience gained by monitoring them informed the work they did on commissioning and planning of health services. We recommend that LINks are given statutory rights to inspect NHS providers in the same way that PPIFs do and CHCs had.

4.2 We are concerned at the intention stated in A Stronger Local Voice that “how members are appointed will be decided at a local level”. This is bound to lead to inconsistency. We believe that there needs to be consistency in the way that LINks operate including the appointment of members. We recommend that a consistent, national approach to appointing members is adopted, even if this is operated locally. Members of LINks should also all be bound by the same Code of Conduct.

4.3 We believe that the proposed “tendering” by local authorities for “host organisations” would lead to great inconsistency and fundamentally would mitigate against having a strong, credible local voice for patients and the public. We have seen how a similar process for “forum support organisations” has not worked for patient forums and in fact has diverted resources away from the coal face. What LINks will need is to have their own staff, for the members and staff to be part of a movement. It is the combination of high quality, dedicated staff working with the appointed members as part of a national movement that made some CHCs so effective. Local organisations operating contracts to “host” LINks will not deliver that. Such an arrangement would also add an unnecessary extra level of bureaucracy and additional costs. Organisations tendering for such contracts clearly need to make additional income for the core functions of their own organisation as well as deliver the contract. It is for these reasons that Parliament agreed in the NHS Reform and Healthcare Professions Act 2002 to the staff of Patients Forums being employed by the CPPIH and deployed to Patients Forums. This is another piece of the legislation which has not been adhered to:

20 The Commission for Patient and Public Involvement in Health

(2) The Commission has the following functions—

(d) providing staff to Patients’ Forums established for Primary Care Trusts, and advice and assistance to Patients’ Forums and facilitating the co-ordination of their activities,

4.4 We recommend that LINks are provided with their own staff (either employed through their local authority or employed centrally by the national body and deployed to local LINks offices) rather than putting contracts for support of LINks out to tender.

Peter Walsh
Chief Executive
Action against Medical Accidents

January 2007
Evidence submitted by the Arthritis and Musculoskeletal Alliance (ARMA) (PPI 149)

INTRODUCTION

The Arthritis and Musculoskeletal Alliance (ARMA) is an umbrella body bringing together 33 national organisations working in the field of arthritis and other musculoskeletal conditions. This includes service user groups, professional associations and research bodies. It is a registered charity.

ARMA welcomes the opportunity to respond to the Health Select Committee’s enquiry. Although drawing its membership from a number of fields, ARMA unites them around a common purpose of improving quality of life for people with musculoskeletal conditions. Our comments will be made in this context.

1. What is the purpose of patient and public involvement?

1.1 To empower citizens, as stakeholders within the local health economy, to influence the future direction and development of health and social care services that they use or may use in the future.

1.2 To improve the legitimacy and quality of decision-making and policy-making within the local health economy by drawing on the experiences and perspectives of the people who use the services.

1.3 To enable local health service providers to be held to account by their stakeholders as the funders and users of the services.

2. What form of patient and public involvement is desirable, practical and offers good value for money?

2.1 Any organised system of patient and public involvement must:

— Be independently constituted outside of any organisation responsible for the delivery of health and social care.

— Enable people from all backgrounds to participate, paying particular attention to the involvement of disadvantaged and underrepresented groups.

— Ensure that a broad range of people who have experience of living with various conditions are involved.

— Support participants in LINks through induction, training and ongoing advice and information so that they can be effective in their roles.

— Foster effective relationships and partnerships with existing relevant voluntary sector infrastructure in the local health economy.

— Have sufficient funding and resources to conduct an effective work programme and to pay the expenses of those who are involved.

— Place a legal duty to consult with it on all providers of health and social care that is either delivered by the local health service, or on their behalf by contract through the independent sector.

2.2 In this submission ARMA would like to pay particular attention to its view that the system should foster effective relationships and partnerships with existing relevant voluntary sector infrastructure in the local health economy.

2.3 ARMA has adopted a successful model of working through its ARMA Local Networks that are currently being piloted in 20 locations in England through a grant from the Department of Health Section 64 Grant Scheme.

2.4 The Local Networks translate ARMA’s successful national model of collaborative working between service users and professionals in order to influence service improvement at a local level. They enable local service users who are involved with organisations such as Arthritis Care, Back Care, Lupus UK, National Rheumatoid Arthritis Society, The Reynauds and Scleroderma Society, National Ankylosing Spondylitis Society and the Scleroderma Society. People from local support groups that are not part of any national body also get involved.

2.5 Arthritis Care (one of ARMA’s member organisations) is also piloting a project that supports service users participation the Local Networks. The project provides support to all service users involved in the networks through phone calls and personal support from regional campaigns managers, as well as tailored residential training events. The training covers meeting dynamics and confidence building, representation issues, local health structures and demystifying medical and NHS language in order to enable service users to participate fully in all aspects of the networks’ work.

2.6 Our evaluation of the first year of the three year pilot has demonstrated that the Local Networks can have a significant impact on service improvement through increasing service user involvement.

2.7 Examples include:

— Developing a service user support centre in Leeds as a collaborative project between the hospital trust and the local voluntary sector.
— Better co-ordination between orthopedics and rheumatology departments in Norwich, leading to improved access to pre-operative therapy.

— In Lancashire and Cumbria a Local Network has successfully lobbied the PCTs to conduct a public consultation when they learnt an independent provider had been awarded preferred bidder status for 60–80% of outpatient work across six specialties without any consultation with services users, health professionals or the public in general.

2.8 ARMA believes that LINks will have better outcomes if they work effectively with bodies such as the ARMA Local Networks. Indeed ARMA would welcome the opportunity for bodies like its Networks to have a formal partnership status with LINks. Such partners would need to fulfil certain criteria around governance, membership and how service users are involved within them to avoid inappropriate relationships that might compromise the independence and integrity of the LINks.

2.9 ARMA would happily provide service users who are involved in our ARMA Local Networks to give evidence of their experiences and to discuss how organisations might partner the LINks.

3. How LINks service should be designed

Remit and level of independence

3.1 LINks should be independently constituted outside of any organisation responsible for the delivery of health and social care. Consortia of voluntary sector bodies already existing within health economies should be strongly considered as a model for hosting and supporting LINks.

Membership and appointments

3.2 ARMA believes that there is significant merit in appointing people who are able to give a wider perspective than their own individual experiences of using services. These could be drawn from a range of people who are active within local charities working within health. Not only can they reflect on their own experiences as service users, but they are also able to consult with a wider network within their own organisations, who often play an important role in improving their members’ capacity to engage effectively in such structures.

3.3 For example, members of the National Rheumatoid Arthritis Society who are involved in ARMA Local Networks are supported in their roles by the NRAS volunteer coordinator. This coordinator shares information about the experiences of others with rheumatoid arthritis with the ARMA Local Network member, who can therefore make a wider, more informed contribution to the network’s work. In turn, the members share network developments with the volunteer coordinator, who can report this information back to others living with rheumatoid arthritis.

Funding and support

3.4 Funding should come from the Department of Health and be guaranteed for a sufficient length of time to enable LINks to be plan strategically and be sustainable over a longer term. Voluntary organisations who are hosting LINks should be encouraged to use a full cost recovery model.

Areas of focus

3.5 The focus of each LINks should be driven by the health and social care needs of the local population. They should focus on strategic issues and complement other means by which service-users can give feedback on current or recent operational matters.

Statutory powers

3.6 It would be beneficial for the statutory power to monitor and report on health services to remain with LINks as they replace PPI Forums, with additional powers in relation to social care being put in place.

Relations with local health Trusts

3.7 ARMA’s Local Networks have demonstrated that a productive relationship can be established between service users and the professionals who are responsible for the delivery of their care. This has been enhanced where managers responsible for planning and commissioning have got involved.

3.8 For example, an ICATS (integrated clinical assessment and treatment services) commissioning group in East Kent recognised the importance of involving the views of both service users and healthcare professionals in their work through and arms-length body. This group therefore approached ARMA in order to foster the development of a Local Network that could contribute to the development of ICATS in a meaningful way, as well as improve musculoskeletal services more generally.
National coordination

3.9 ARMA recognises the value of having a national organisation that provides a central strategic resource body that would:

— Gather and share good practice about innovations in patient and public involvement.
— Foster the development of LINks through providing advice, support and training.
— Raise the profile and priority given to patient and public involvement in national policy-making.

4. In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

4.1 ARMA believes there would be some circumstances that will affect service users that would necessitate a wider public consultation. It is ARMA’s view that service users, through LINks, should be involved in the design and development of the consultation process to ensure that it is accessible and focussed on the best interests of users.

Bill Freeman
Director, The Arthritis and Musculoskeletal Alliance
January 2007

Evidence submitted by Arthritis Care (PPI 130)

Arthritis Care represents the interests of the nine million people in the UK with arthritis, through peer support, access to information and self management training, and campaigning to improve the quality of life for people with arthritis.

Arthritis Care welcomes the opportunity to respond to the Health Select Committee’s inquiry into patient and public involvement. As an organisation, we take user involvement very seriously, both internally and externally. We are working with our volunteers, members and supporters to develop competency skills for more effective engagement with decision makers at a local level. We recognise that user involvement can be hugely rewarding and empowering as an end in itself.

Arthritis Care would be willing to give oral evidence to the committee if this was requested.

1. What is the purpose of patient and public involvement?

1.1 To involve non-professionals in influencing health decision-making locally in order to improve the full range of health services that people use.

1.2 To support healthcare organisations to be more accountable to users and to strengthen their capacity to respond to the public’s views.

1.3 It is important to understand that people who use the health service not only have a right to determine how it is planned and delivered but also that their experiences of what is effective and what is not are crucial to a full understanding of how to maximise efficiency and effectiveness.

2. What form of patient and public involvement is desirable, practical and offers good value for money?

2.1 Some PPIFs have been very effective whilst others have not. It is important to look at the successful models and consider whether and how they can be exported elsewhere. A model that has worked well in one area may not be appropriate in another, or an equally good but different approach may work just as well.

2.2 There are some key principles, though, that are likely to be met in any successful model:

— People should also ensure that their contributions are representative of the experiences or aspirations of a significant group of users and do not merely reflect their own personal views.
— Ideally, people involved in PPIF/LINks are in touch with a wide group of service users and are able to act a two-way link between the PPIF/LINks and this wider group.
— The local NHS and social care structures must take PPIF/LINks seriously; they need to recognise the important role and unique knowledge and experience being introduced to commissioning and planning discussions and make genuine efforts to incorporate the networks into their key decision-making cycles.
— The PPIF/LINks must themselves recognise the enormous complexity of NHS and social care planning and delivery and attempt to understand the barriers and constraints that affect planning and delivery.
— A positive dynamic should exist between service users, professionals, planners and commissioners. Each sees the role of the others as important and discussion and debate is structured accordingly.

— Service users receive good training, induction and ongoing support so they are able to contextually their experiences and opinions into the framework in which NHS and social care bodies are operating.

— People involved in PPIF/LINks should be able to think strategically and not focus narrowly on operational issues (unless these are so large they are threatening efficient delivery).

2.3 Arthritis Care and the Arthritis and Musculoskeletal Alliance (ARMA) are involved in an innovative pilot project that is bringing together patients, health professionals, commissioners and planners in a series of local networks around England to improve the planning and delivery of services in the area of musculoskeletal medicine.

2.4 In addition to direct involvement in the pilot networks, Arthritis Care is additionally developing a project that will train and support users to contribute effectively to the deliberations of each network. Both projects are funded by the Department of Health and ARMA will send a separate paper to the committee giving more information about the project.

2.5 Early indications suggest that the pilot networks are contributing in a very positive way to assessing and improving services in those areas. If this approach continues and is sustainable it may be a format that could be adopted in other disease areas. Whilst we are not yet ready to suggest a formal federated structure, it would certainly benefit LINks to have representatives from some disease areas who are working in a deeper way within their particular part of the health economy.

2.6 From observation, the NHS supported Cancer Networks also appear to offer a model for effective group work. Non-professionals (offering their views and articulating the needs of cancer patients) working with health practitioners in a single group seems to generate a higher regard by health professionals for contributions made from “the user perspective”. The key needs of people who have cancer can then be clearly communicated by “informed” health professionals along the “care pathway” to other health professionals and health decision makers.

2.7 If the future LINks meetings bring together colleagues from across the specialist care units (on a rolling basis), healthcare commissioners, GPs, Primary Care Trusts and acute Trusts, the independent healthcare sector, patient groups (on a rolling basis), the voluntary sector, Strategic Health Authorities, Regional Government Development Agencies and Local Authority Adult (Social) Care Services the opportunity for more “joined up” decision making would present itself and further improve health and social care professionals’ opinion of the value of patient and public involvement in decision making.

2.8 The power balance needs to be redressed in the health and social care sector between “commissioner” and “user”. Government legislation already enshrines the value of the “patient voice” in local health decision making. The service user contribution to decision making needs to be properly valued by all stakeholders.

2.9 Professionals will be better able to make informed decisions about local health and social care needs as a result of the valued input of the user perspective. The intangible wariness with which the “commissioner” and “user” approach each other could, and should, become a thing of the past. A mutual appreciation of the “PPI process” to reach reasonable planning decisions would be strengthened.

2.10 Future LINks networks need to be less strictly governed by a central authority. Whilst a minimum standard of “Terms of Reference” would be required, the specific way by which the LINks operate on a day to day basis should be given over to the constituent members—thus retaining ownership and a sense of self-regulation. Too much time, energy and goodwill was previously lost due to the centralised requirement for strict adherence to the rules.

2.11 The nature of the commitment required to participate effectively in PPIFs to date has determined the composition of most fora. PPIF/LINks need to be much more representative of their local population not only in terms of gender and ethnicity (including people whose first language may not be English) but also of age and life stage (eg people in mid-career and young people including those who are in full-time education).

2.12 Full consideration should be given to the advantages and disadvantages of introducing a form of payments for participation in LINks, perhaps similar to the local authority attendance allowance scheme for elected councillors. If this could be done without distorting the motives of those who put themselves forward for LINks it could go some way to widening the range of people able to make the significant commitment necessary to make LINks effective. Certainly, LINks membership needs to better reflect the population as a whole than has perhaps been the case with PPIF.

2.13 Accessibility is key—the LINks need to be seen to be as genuinely “open” groups and to offer meetings at times to suit participants. Health and social care professionals tend to prefer to hold meetings during office hours. If LINks Networks are able to hold meetings at times likely to attract health and social care professionals the attendance by healthcare staff is likely to increase and thus encourage more joined up working across health and social care departments.
2.14 Email and written submissions must be given the same weight as personal contributions at meetings. This should allow a broader cross section of the community to contribute even if they are not a full and regular member of LINks.

2.15 The report of LINks meetings could appear in the local newspaper thus informing the wider general public of issues which affect us all. Appeals for contributions of views from the general public about a topic to be discussed could be canvassed in the local newspaper column. The voluntary sector could offer support to people who have not previously become involved in community decision making meetings. They could help to prepare individuals to learn how best to make a positive impact at LINks meetings and feel a valued participant.

2.16 The future PPI “resource centre” (designed to support health professionals and social care organisations) does not appear to have the needs of individual service users at its centre. Therefore an additional facility to support the individual LINks participant would be required to enable individual members of the community feel that they were participating as an equal partner in LINks.

3. Why are existing systems for patient and public involvement being reformed after only 3 years?

3.1 Although the principles of patient and public involvement are important to support, many of the PPIFs have been ineffective. For LINks to work not only must there be “buy-in” from other areas of health and social services to ensure the views of LINks are taken seriously but the recruitment policies, training, induction, ongoing support and resourcing must be robust.

3.2 A further failure will fatally undermine the entire concept of patient and public involvement in health and social services planning and this would be disastrous.

4. How should LINks be designed, including:

Remit and level of independence

4.1 LINks should be independent of Local Authority and Primary Care Trust funding. Ideally, funding should come direct from the Department of Health according to pre-agreed formulae relating perhaps to the population of the area covered.

Membership and appointments

4.2 Membership and appointments should be handled by a dedicated team at the Healthcare Commission whose interests are the furtherance of PPI. It is important that appointments are independent of the health and social services bodies with which the LINks are to be working.

4.3 In addition, there should be criteria developed that reflect not only the specific skills that should be expected of each individual LINks member but which also ensure that LINks are as representative of their local health economy as is possible. This should have regard to the diversity of the population as a whole as well as to different types of medical conditions.

Funding and support

4.4 External financial support of the LINks by the Department of Health should prevent a skewing of decision-making towards any particular benefactor. Local health scrutiny has previously been compromised due to the funding arrangements of PPI Forums.

Areas of focus

4.5 The health and social care needs of the local population should be the main focus for LINks. The focus of LINks needs to be much more strategic than has sometimes been the case in the past.

4.6 Understandably there has been a great interest previously by PPI Forum members in the level of cleanliness of hospitals within their region of influence. It should be borne in mind though that there are currently over 80 agencies undertaking inspections in hospitals (including hygiene). It is not clear to the casual onlooker the “added value” of an inspection visit to a hospital made by a small group of PPI Forum members.

4.7 There would also be a greater understanding by the general public (and willingness to become involved in the work of the LINks) if they were able to contribute to local impact assessments. These could be in the form of LINks canvassing local opinion throughout their geographical region on the specific needs of people who use NHS health and social care services.
Statutory powers

4.8 A passing over from PPI Forums to LINks of the statutory power to monitor and report on health services would be highly beneficial to the work of LINks and the impact of PPI on influencing health decision making. Similar powers in relation to social services are also needed.

Relations with local health Trusts

4.9 LINks should be considered by healthcare professionals and allied health professionals as an equal partner in the drive to make patients at the centre of health decision making.

4.10 LINks could become a useful conduit of information and support between health and social care teams trying to unite their (at times) disparate methods of working to achieve the united goal of better public health.

National co-ordination

4.11 Apart from timely steers using national policy guidance notes, there does not appear to be need for national co-ordination of the work of the LINks. The reasoning behind this is that each PCT, Acute Trust and (more importantly in the future) Foundation Trust sets its agenda in response to the commissioning needs analysis.

4.12 It is hoped that LINks could plan their annual priorities in consideration of the agreed priorities of the local authority social care services and health care services. LINks’ chosen areas of work could then complement the work undertaken by health and social services decision makers and support better use of PPI.

4.13 There may be some benefit to some form of regional-based co-ordination perhaps mirroring Strategic Health Authority boundaries.

5. How should LINks relate to and avoid overlap with

Local Authority structures including Overview and Scrutiny committees

5.1 LINks should have a direct link into the work of the Overview and Scrutiny Committees, ensuring transparency of decision-making.

Foundation Trust boards and Members Councils

5.2 LINks should approach Foundation Trust Boards and Member Councils in the same way they would approach the Primary Care Trusts and Acute Trusts. An even handed approach with all healthcare services will ensure that LINks are treated as an equal partner in the PPI process.

Inspectorates including the Healthcare Commission

5.3 LINks should inform inspectorates of their work programme for the next quarter so that there is a reciprocal flow of information about reviews and findings. This should help inform Inspectorates and LINks about areas in which to concentrate their relative influence.

Formal and informal complaints procedures

5.4 LINks should not become involved in any type of informal complaints procedures. The existing ICAS (Independent Complaints Advocacy Service) complaints supporting mechanism for members of the public (and existing procedures within local authorities) should be maintained alongside LINks.

5.5 The role of LINks is strategic and should not cover individual complaints and concerns. However, LINks should have the right to see aggregated statistics regarding complaints in case they reveal general problems that need addressing.

6. In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take.

When local service users will be affected by a change in the provision of health or social services provided.

Martin Jones
Senior Campaigns Manager, Arthritis Care

January 2007
Evidence submitted by the Association of the British Pharmaceutical Industry (PPI 79)

1.1 The Association of the British Pharmaceutical Industry (www.abpi.org.uk) is the trade association for about ninety companies in the UK that research and produce prescription medicines. The Involved Patient Initiative Taskforce (IPI) of the ABPI has been working with patient groups to encourage and improve patient centred care across the health sector.

1.2 The IPI mission is:

To further ABPI involvement with patients and patient groups, by fostering a broad dialogue across a range of issues that affect people’s health, including the discovery, development, supply and use of medicines and to find ways in which we can better meet their needs and ultimately, improve the health of the public.

1.3 Within IPI we are working to:

— Encourage involved patients
— Engage with patient groups and stakeholders
— Advocate best practice in medicines information
— Facilitate partnership approaches
— Improving access to medicines information
— Putting patients at the centre of our work

2. ABPI RESPONSE TO THE HEALTH SELECT COMMITTEE INQUIRY

We would like to respond in particular to two questions raised in the inquiry, namely:

“What is the purpose of patient and public involvement?” and “What form of patient and public involvement is desirable, practical and offers good value for money?”

2.1 What is the purpose of patient and public involvement?

There is a growing recognition of the need to improve the availability, quality and accessibility of information about medicines for the public. This is being driven by a number of stakeholders including patients themselves, the Government, the NHS, the regulatory authorities and the pharmaceutical industry. An informed patient knows that treatment options exist; is more able to have a successful consultation with health professionals, and is more likely to take medicines as prescribed, leading to better outcomes for patients, families, health professionals and the NHS. The ABPI actively supports the Ask about Medicines activities which encourage the availability of medicines information to patients.

2.2 Increased patient involvement in decision making during all aspects of patient care relies on appropriate information. Healthcare providers need to help patients in understanding better by providing them with high quality information about their care. This is why the ABPI has been working with its member companies to support the Department of Health’s information strategy.

2.3 Why is it useful for patients to have information about medicines?

— Informed patients are better able to take charge of their own healthcare. This is welcomed by many healthcare professionals and also by the pharmaceutical industry, as it leads to better patient understanding, better compliance with medication and less wastage.

— By engaging in an informed dialogue with their doctor, patients are more likely to take an active role in tackling their illness—not just with regard to medicines, but with other aspects such as lifestyle and dietary changes.

2.4 What form of patient and public involvement is desirable, practical and offers good value for money?

In the last two years the industry has been working with Cancerbackup and Diabetes UK to highlight current information gaps and to offer solutions. Together with our partners and Ask about Medicines we have produced the CancerMaze report\(^1\) and the Diabetes Jigsaw report,\(^2\) which highlighted the shortcomings in the area of information provision for patients. We are currently working with our partners to explore and develop the information prescription concept—the idea to develop personalised information signage for patients.

Information prescriptions, provided by the healthcare professional at the time of consultation are an individualised way to “signpost” patients to appropriate sources of further information and support. The prescription would be given following discussions about the patient’s concerns, fears and information needs surrounding their diagnosis and treatment.

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3.1 Example Diabetes

The Diabetes Information Jigsaw report found that there are significant missing pieces of information for patients about their diabetes. In particular, more than a third of people with diabetes are unaware that they will have the condition for life and half don’t know that diabetes can reduce their life expectancy.3 Partly as a result of this missing information, nearly two thirds (65%) of people with diabetes are not taking their medications as prescribed, and one in three people don’t understand what their diabetes medications are for or how to take them because they feel stupid asking questions. Over half (57%) find it difficult to ask questions because they feel there is not enough time during the consultation to answer all their queries or their doctor seems too busy. Perhaps most worryingly a quarter (25%) don’t understand what their medicines are for or how to take them because despite having asked, they don’t feel their doctor or nurse sees the benefit in informing them.

3.2 The Diabetes Information Jigsaw survey also revealed that 60% of people with diabetes don’t know as much as they would like about their treatment options. One reason for their confusion is that they have a poor understanding of medical terms and phrases commonly used in consultations, with nearly a fifth (18%) not understanding as much as they would like about their treatments because they can’t understand what their doctor or nurse is telling them. To make matters worse over a third (36%) don’t even know what questions to ask about their treatment options.

3.3 Therefore, in order to empower people with diabetes to communicate with their healthcare professional and help improve their understanding of medicines, the ABPI in partnership with Diabetes UK and Ask about Medicines has produced the following two resources:

3.4 A booklet Ask About Your Diabetes Medicines4 contains questions that people might want to ask healthcare professionals involved in their treatment throughout their diagnosis and treatment path. It also signposts people to further sources of information, including patient friendly Medicine Guides for Diabetes which are available on www.medicines.org.uk. The new Medicine Guides provide easy to understand information about every diabetes medicine to help people with diabetes use their medicines safely and effectively, and make better informed choices about treatment, with their health professional.

3.5 Medicine Guides have been developed as part of the Medicines Information Project (MIP)5, which is creating a new comprehensive structured source of information about medicines alongside information about the condition and all the treatment options. Medicine Guides are linked to information about the condition and the range of treatment options available, provided via NHS Direct Online.

3.6 These two resources aim to help people make better informed choices about treatment, with their health professional, and to understand and use their medicines safely and effectively.

4. Example Cancer

4.1 The Cancer Information Maze is a report which draws together existing research, literature and opinion and contributes to better understanding of patient attitudes, beliefs and experiences of cancer medicines information. The report highlights that people who have cancer feel lost in a maze of information and are failing to understand their condition. The report was launched on 15 November 2005 to the media and was presented to the Department of Health by Ian Gibson MP, Chair of the All Party Parliamentary Group on Cancer. One of the calls made in the report is the need to develop the information prescription concept and provide information signposting to patients.

5. Conclusion

The industry would like to be seen as one of the providers of medicines information so that it can give each patient the information they desire. All patients should have access to information about their condition, the treatment options available and the risks and benefits of different options, relative to their own situation. Easy access to high quality, reliable patient-friendly medicines information is key to enabling people to:

— Understand their medicines better;
— Participate in decisions about their own treatment; and
— Make use of the medicines they have been prescribed.

Association of the British Pharmaceutical Industry

January 2007

3 Awareness of diabetes and Diabetes UK amongst the general public published by Diabetes UK/MORI February 2006.
4 Ask About Your Diabetes Medicine, booklet published by Ask About Medicines November 2006.
5 Medicines Information Project—a multidisciplinary working group working to improve medicines information to patients and carers (www.medicines.org.uk).
Evidence submitted by Asthma UK (PPI 103)

Asthma UK welcomes the opportunity to submit a response to the Health Committee’s inquiry on patient and public involvement in the NHS. As the voice of people with asthma, Asthma UK is a proactive organisation that puts people with asthma first to offer solutions which improve the quality of life for people with asthma.

Asthma UK is the charity dedicated to improving the health and well-being of the 5.2 million people in the UK whose lives are affected by asthma. We work together with people with asthma, their carers, health professionals, and researchers to develop and share expertise to help people increase their understanding and reduce the effect of asthma on their lives.

We would particularly like to draw the attention of the Committee to the following points:

— Effective patient and public involvement improves services and brings benefits for service users, communities and the NHS
— Asthma UK is carrying out several projects intended to secure PPI in our own work and promote it in the health service.
— The establishment of a system in which LINks are given the powers and support to genuinely and effectively represent local communities is essential.
— Previous experience of PPI must be put to use in planning and implementing the new system.
— Asthma UK is especially keen for PPI in commissioning to be more robust and is working collaboratively with other leading charities to produce a web-based toolkit which will facilitate the work of commissioners in this area.

What is the purpose of patient and public involvement?

1. Well-implemented strategies for patient and public involvement hold substantial benefits for patients, carers, for communities and for the NHS. Only by ensuring the involvement is effectively sought can we secure mutual understanding and constructive dialogue between all those who use or work in the NHS.

2. The potential benefits for patients, service users and carers substantially lie in the improvements in service design and delivery that can develop from effective input. Through effectively mapping and understanding the patient journey and user experiences in collaboration with those who experience services, gaps in, and quality of, provision can be identified and the best mechanisms for service delivery can be developed. The additional information accessible to fully engaged patients may also affect demand and drive up standards through the exercise of choice. Patients also stand to benefit through being empowered to directly affect decisions about health, which will Lead to a more comprehensive interest in their conditions and a more constructive relationship with health professionals, improving concordance and helping to empower a greater number of patients to manage their own conditions.

3. The purpose of patient and public involvement from the perspective of communities is in securing a genuine say for local people and voluntary sector organisations. This, in turn, will increase legitimacy for decisions made on behalf of local people and improve public confidence in the services they receive.

4. These benefits are also of considerable value to clinicians and managers in the NHS. Better, more appropriate services should be a critical aim for NHS sta,

What form of patient and public involvement is desirable, practical and offers good value for money?

5. There are certain principles that should run through all plans for patient involvement:
— Policy must be designed to ensure that it is inclusive, accessible and makes a positive difference to patients' health.
— There is no single or best way to secure patient, user and carer views. Patient and public involvement need not necessarily take on a single prescribed form at either national or local level, and we would not wish for national guidance to inhibit local innovation. Nevertheless, Asthma UK would like to see more evidence of commitment from the Department of Health to ensuring that involvement is embedded in some form across all functions of the health service and that LINks are given every opportunity, necessary support and effective powers to flourish and meaningfully represent local interest in health and social care.

6. Asthma UK seeks to ensure that people with asthma are engaged with our work through a number of mechanisms, many of which could be employed more widely. These include the development of health promotion materials in 25 languages, regular surveys and focus groups, and our Speak Up For Asthma volunteer programme.
7. A substantial current project is the development of a User and Carer Advisory Forum, for which we are now recruiting members. Asthma UK places huge emphasis on listening and responding to the needs of people affected by asthma, and the new forum is an important way to do this. Meeting four times a year and being broadly representative in terms of the diversity of the UK population, it will provide a communication channel between people with asthma, and carers of children with asthma, and Asthma UK staff and Trustees. The new forum will help contribute to shaping the way we do our work, the issues we engage with and what people with asthma and their carers think is important in improving the quality of life for people with asthma.

8. We are also seeking to enable commissioner to more effectively involve patients and the public in their work by developing a web-based commissioning toolkit for long-term conditions. This ground-breaking project is being developed in collaboration with the British Heart Foundation and Diabetes UK, and includes extensive advice on how to involve patients in each stage of the commissioning process. It also provides the opportunity to access a comprehensive library of related documents and to share good practice via case studies and a discussion forum.

9. Numerous other demonstrations of good practice in patient and public involvement can be identified. In 2004, for example, the London Borough of Newham produced a particularly effective review of asthma services, beginning with a public meeting and continuing to involve people with asthma as members of the Health Scrutiny Commission group throughout the review process. In 2006, Asthma UK’s Challenge Fund provided support for the Adolescent Asthma Action and Help (AAAH) Project, a scheme in which a group of teenagers in Dudley produced a video resource for schools in order to explain the effects of asthma on their lives. Work such as this is greatly valuable, and similarly innovative projects should be actively promoted elsewhere.

How should LINks be designed?

10. Asthma UK would welcome the introduction of LINks centred around communities and patient journeys and coterminous with local government and PCTs. If they are carefully structured and given the appropriate support, these have the potential to build on the work of Patient and Public Involvement Forums (PPIFs) and take forward the way in which patients can participate at a local level. The establishment of LINks presents an opportunity to build on best practice, develop improvements and to demonstrate a real commitment to the practical implementation, as well as the principle, of patient involvement.

Remit and level of independence

11. There are some risks in arranging for LINks to be hosted by organisations outside the public sector. While we can appreciate the benefits of flexibility to local needs and of engagement with different local groups, we are concerned that local variation may make LINks substantially less effective in some areas than in others. We are also concerned that in being coordinated outside the NHS and the local authority, LINks may be easily sidelined. This must not be allowed to happen. Nevertheless, independence from government is an important principle, and the contribution that third sector host organisations can make in engaging with local communities and in implementing innovative practices is invaluable. Perhaps an evaluation of the arrangements for PPIF support would be helpful in order to extract lessons for the future.

Membership and appointments

12. Recruitment to LINks is a key concern in their establishment. Effective recruitment based on a community empowerment model takes time, particularly when aiming to engage people not traditionally involved in health decision making. This should be acknowledged in the planning process. Asthma UK recommends that government should learn from the experiences of CPPIH in recruiting to forums since 2003 and also from the voluntary, patient and community sector. Including membership of a LINk as a recognised public duty would also be useful in attracting patients and the public to participate.

13. There must also be a mechanism to engage with more patients, particularly with patients who have not had the opportunity to raise their concerns in the past. Local and national charities including Asthma UK should be able to help secure more comprehensive community engagement.

14. It is also important to recognise that retention is as important as recruitment and that members will only stay if they feel valued and well supported. Members should be reassured that they will be have any additional needs fully met through the provision of services such as interpreters, signers, and provision for meeting carers’ costs. They should also be offered speedy reimbursement of all out of pocket expenses including loss of earnings and, where requested, they should be given payment in advance for potential expenses.
15. For some of the same reasons, LINks should not place too high a demand on participants. Many people found that the time required by Patient and Public Involvement Forums was too much for them. Like many long-term conditions, the impact of asthma on quality of life can fluctuate over time, so it can be difficult for people with asthma to make substantial commitments.

Funding and support

16. Funds must be made secure and ring-fenced. It should not be possible for local authorities to divert money away from LINks to fund unrelated projects: doing so would undermine the credibility of the LINk organisation and inhibit its ability to function effectively.

Areas of focus

17. The focus of LINks should not be excessively restricted, and must be allowed to evolve in order to adequately address local concerns. Nevertheless, the particular focus on mental health services, ambulance services and specialist trusts which PPIFs have delivered in some areas, could valuably be retained. Consideration could also be given to developing joint working arrangements between LINks with regard to these particular services as they often cover multiple boroughs and, in the case of specialist trusts such as Great Ormond Street, may be national.

Statutory powers

18. We would suggest that LINks inherit the full range of statutory rights of PPIFs as well as being given the right to be formally consulted on substantial variation in service provision. Having the right to be formally consulted and, if necessary to refer matters to the Secretary of State for Health, would confirm that LINks were bodies with meaningful powers in matters of considerable public interest such as hospital closures or service reductions. LINks should also have clear powers to refer matters of concern to Overview and Scrutiny Committees for review.

National co-ordination

19. As indicated above, there is much to be learned from the experiences of CPPIH in this area. Some more indication from the Government of what—if any—institutional arrangements will be made for LINks at the national level would be very welcome. It is Asthma UK’s understanding that National Voices is not intended to be a co-ordinator or national representative of LINks. If this is the case, then the nature of the relationship between LINks, National Voices and any proposed successor organisation to CPPIH should be made clear from the outset.

How should LINks relate to other organisations and avoid overlap?

20. Local Authority structures including Overview and Scrutiny Committees

The Department of Health’s latest guidance leaves the precise nature of the proposed relationship between LINks and OSCs unclear. It is specified that LINks will be independent but have the power to refer matters to OSCs and receive an appropriate response. However, it is also indicated that the LINk will only be able to take an active role in OSC review activities if the OSC deems this to be useful.

In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

21. Asthma UK is keen to see the improvement of patient and public involvement in general, but we are specifically concerned about how it is implemented by commissioners. We are pleased that the duties to involve and consult patients and the public are to be clarified, and that the duties of commissioners have been extended to incorporate responding to the community. The PCT prospectus proposed by the Department of Health is certainly one mechanism through which this can be achieved. However, Asthma UK feels it would be more productive to ensure that commissioners fulfil their duties to both consult with and respond to patients and the public in a more systematic and coherent way.

22. Commissioners must be genuinely open to receiving the views of the wider public, and to acting upon them. They should be proactive in reaching out to local people—by polling, by arranging to meet community members and leaders and by making connections with the newly established LINks. Responding to the community should be an integral part of this process; commissioners can feed back within their own meetings and through LINks, but they should also make their commitments explicit at the end of any period of public consultation, and ensure that they report on how well their plans to meet these commitments are progressing. This can then inform public consultation in subsequent commissioning cycles as part of an ongoing relationship between commissioners and patients.
Evidence submitted by Avon, Somerset and Wiltshire area PPI Forums (PPI 89)

INTRODUCTION

1. This response to the Health Select Committee Inquiry into future patient and public involvement arrangements is submitted on behalf of around seventy members drawn from PPI Forums operating in Bath and North East Somerset, Bristol, Gloucestershire, North Somerset, South Gloucestershire, Swindon and Wiltshire.

2. This report is the feedback of discussion groups considering future public involvement issues that took place at a Members’ Conference in Warminster, Wiltshire on 1 December 2006. Details of the inquiry terms of reference were not known at the time that the Conference agenda was planned—so the feedback is either directly attributed to relevant questions posed by the Committee or included as additional comments.

3. The report has been compiled by staff of the Health Advocacy Partnership, a not-for-profit Forum Support Organisation operating in Avon, Gloucestershire, Somerset and Wiltshire.

4. The views reported as bullet points to each question are as agreed by the members participating in the Conference and are submitted without amplification.

QUESTIONS POSED BY THE SELECT COMMITTEE

5. What is the purpose of patient and public involvement?
   — to become a national / local body and voice of the public;
   — to be the eyes and ears of the public (not the NHS)

6. What form of patient and public involvement is desirable, practical and offers good value for money?
   — to contribute a public perspective to the Healthcare Commission’s Annual Health Checks;
   — to carry out and report on health related activities, visits, and surveys;
   — to respond with a public view to crisis’s as they arise;

7. Why are existing systems for patient and public involvement being reformed after only 3 years?
   No specific view expressed—apart from the general conclusion that there is a risk of losing experience and expertise—and it seemed to be a bit of a waste of money.

8. How should links be designed, including

8.1 Remit and level of independence
   — make patient’s voice heard and be the eyes and ears of the public—not the NHS;
   — there is a need to retain independence from PCT and other provider organisations;
   — contribute to Healthcare Commission’s annual Health Check;
   — produce Forum Annual Report;
   — work with local OSCs and regulatory bodies;
   — clear definition of role and responsibilities;
   — respond to crises as they arise;
   — listen and monitor your Trust/patient outcomes; and
   — have more statutory powers.

REFERENCES


Donna Covey,
Chief Executive, Asthma UK
10 January 2007
8.2 Membership and appointments

Important to:
- maintain adequate numbers of members to achieve work plan priorities;
- determine whether existing Forum members are willing to continue;
- keep members motivated and involved;
- actively recruit for communities, groups and local people;
- achieve continuity and clear communication;
- have clearer definition of members’ role;
- devote time and resources to team building;
- set achievable targets in LINk work-plans, and regularly review;
- prioritise “what” members do; and
- participation should be recognised as a public duty—just like jury service.

8.3 Funding and support

Important to:
- provide adequate funding to support and complete projects;
- avoid time wasting activities;
- reduce number of meetings;
- enable members to allocate resources;
- continual support to complete projects—this has resource implications; and
- maintain support for hospital visits—and to other facilities.

Members discussed question: what training should be provided to help participants participate effectively?

- What will LINks consist of: structure; support organisation; working arrangements; need to know what LINks do to define training.
- Training on “what is a LINk”.
- Statutory duties and rights.
- Provide information not just training.
- Specific training on the issue in hand; ask the right questions.
- Relevant communication.
- How to conduct and behave in a meeting objectively.
- How to communicate with the public.
- Calling on experts.
- Health and social care education.
- Time management.
- To know who runs LINks.
- Leader of each network with a clear vision and mission.
- Leadership training.
- Job description for volunteers and training on this.
- Initial—understanding NHS structure.
- Explaining how LINks will work.
- Clarity on statutory powers.
- Ensuring commitment from a “sense of belonging”.
- Training for specialised areas eg visiting; PR; checking Trust Literature etc; Public meetings eg use of microphones.
- Who will decide? Who is trained at what in which way? government; members of LINks; support organisation.
8.4 Areas of focus:

— Set achievable targets.
— Current PPIF activities that should carry forward to focusing LINk activities include:
  — Treatment for long term conditions.
  — Staffing levels.
  — Infection control.
  — Social Care.
  — Maternity Services.
  — Dentistry.
  — Access and Transport Project.
  — Carer’s Project.
  — Patient Choice.
  — Mental Health issues.
  — Acute—ongoing project work (eg delayed discharge; “essence of care”).
— Visits—with a purpose and value.

8.5 Statutory powers

Members discussed question: what powers do you think LINks should have?

— Impossible to say until the actual structure and membership is made clear, but LINKs need to be represented on relevant bodies eg NHS Trust Boards, Social Services Committees, OSC.
— All existing Forum powers should be retained.
— To have staffed office in each OSC area.
— Right to access—short notice, 1 hour; right to require information.
— Find out about complete package of care and monitor.
— Right to verify independently what is going on.
— Cover social care and health.
— Sit on boards—PCT; hospitals; social services.
— Right to know how response to complaints have been carried out.
— Check if individuals (with patient’s consent) care package has been implemented.
— Right to challenge government.
— To require PCTs/Trusts to work with LINks.
— Right to monitor and report with recommendations.
— Make visits to NHS and social care facilities, including:
  — including short notice visits; and
  — community hospital/centres.

8.6 Relations with local Health Trusts

— Contribute to annual Health Check.
— Right to report on Trust activities and receive a response.
— Forge independence from PCT and other provider organisations.

8.7 National coordination

— Encourage some projects to be done nationally.
— Gather information “statistically” on one subject—at national level with regional breakdowns.

9. How should links relate to and avoid overlap with

9.1 Local Authority structures including Overview and Scrutiny Committees

— Contribute to OSC reviews.
— LINks be represented on OSCs.
9.2 Foundation Trust boards and Member Councils
   — Share membership—foundation members can also be members of local LINks.

9.3 Inspectorates including the Healthcare Commission
   — Contribute to reviews and reports.
   — Suitably trained members to be part of inspection teams.

9.4 Formal and informal complaints procedures
   — Receive regular reports on local trends.
   — Use complaint trend reports as evidence to support work-plan priorities.

10. In what circumstances should wider public consultation (including under section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

10.1 Not discussed.

11. Other Issues

   The Conference considered a number of other issues—not directly related to questions posed by the Health Select Committee. However, members asked that their views be shared with the Committee as they believe that some of the issues remain relevant. These are:

11.1 How can individuals participate effectively in LINks?
   — Facilitate communication between the public and LINks eg walk in centers; letter; third parties.
   — Need more information and case studies before people can work effectively.
   — Who will provide the link between HAP? and vested interest groups to provide fairness and balance to ensure generic issues are covered eg hospital cleanliness.
   — Existing Forum members could be in a “pool” to conduct visits etc to hospitals/surgery’s etc—members already have CAB checks and training.
   — Join LINks.
   — Join other organisations in strategic partnership; community’s.
   — Encourage people to comment and feed in at “source” of treatment which is then taken forward to LINks.
   — Encourage increased membership to other organisations and LINks.
   — Lay inspectors (volunteers).
   — Activate communication to general public about LINks—and to other organisations eg WI’s; Rotary; Lions.
   — Focus groups and public meetings.
   — Start working with young people through citizenship/personal and social education so they become active citizens for life.
   — Provide a real effective host organisation with contractual remit to involve widest section of community possible.

11.2 How would you like to see links operate?
   — Panel selection—dependence; open application; non-political.
   — Core Group—engender continuity, ideas and sense of membership.
   — Will need training.
   — Change the name to distinguish from other “LINks”.
   — Simple access to IT for users and alternative access link—need IT.
   — people in place for people to “use” to obtain info.
   — Good media contacts.
   — Need a national/body voice—well defined structure.
   — “Core Group” needs chair/named contact—defined role of chair/facilitator.
   — Involvement—sub groups attracting interested people.
— Publicity to attract people.
— Link with health/social services; care groups—many already contacted, need to build on this.
— PPIF Members to be invited to be “members” of LINks chance to make use of past experience—committed, continuous membership.
— National and local support organisation.
— More support than now.
— Reasonable expenses.
— “Chief Executive” and admin support.
— Vetting of voluntary sector organisations.
— Transparent and objective selection of groups and individuals.
— Inclusion of non-computer experts.
— Support for “Right of Access”.
— Leave of absence for employed members to attend meetings/activities. General consensus to encourage younger members to join, invariably this can only happen if legislation allows individuals to take paid leave from their place of employment. Full support of employers will be needed to make this happen.
— Public need to know that LINks will be permanent not transient
— Remember that PPI/LINks are voluntary and independent.

11.3 What can LINks do to engage the public effectively?
— More planning: learn from mistakes made when setting up Forums; clear focus and expert delivery; clear points of contact.
— Promotion exercise: effective marketing; robust properly funded publicity; resources—major! to ring fence—no shoe strings allowed; show that LINKs has power; lack of resources will indicate that government are cheapskates.
— Government need to heed feedback from Patient Forums and not repeat the same process with LINKs that they did with PPI.
— Inform public and convince them to become involved.
— PCTs to be paid on results.
— Build profile to dissolve apathy.
— To be seen to support the public in their concerns.
— Named permanent contact point.
— Encourage young people and ethnic minorities to apply.

11.4 What can realistically be achieved for LINk work plans?
— Depends how hard you work with membership.
— Avoid time wasting activities.
— Do the best we can with resources we have got.
— Use smaller working groups.
— Produce Annual Report and contribute to annual Health Check.
— Carry out monitoring visits.
— More work less meetings.
— Guidelines on how to conduct meetings.
— Complete “Must do” items.
— Less than you think.
— Depends on who is listening to us.
— Forward planning with short term activities that are achievable.
— Commissioning from PCT’s and GP’s.
— Treatment for long term conditions.
— Include social care.
— Fully understand NHS and PCT provider issues.
— Access issues—transport and parking.
— Swiftly identify priorities then swiftly identify project.
— Patient choice (Swindon and Great Western Hospital).

12. Conference agreed that these general points do not preclude other comments being submitted by individual Forums or members—recognising that the views expressed reflect the experience of members, which may be different from other areas.

Nick Westbrook
Health Advisory Partnership
10 January 2007

Evidence submitted by Barnet and Chase Farm Hospitals NHS Trust PPI Forum (PPI 13)

What is the purpose of patient and public involvement?

PPI Forums have statutory powers which allow them to provide a valuable independent perspective on services provided by the Trust. This should continue in any new arrangements.

What form of patient and public involvement is desirable, practical and offers good value for money?

Why are existing systems for patient and public involvement being reformed after only three years?

To allow one Forum to monitor all the health services provided to a community in place of separate Forums being concerned with hospitals, primary care services, ambulances, special needs and so on.

How should LINks be designed, including:

Remit and level of independence

To look after the needs of patients and the public by monitoring services independently.

Membership and appointments/Funding and support

In our view LINks should be composed of an amalgamation of existing PPI Forums to which are added people concerned with health and social care services and cultures not currently represented. The Forums could, at least initially, form sub-committees of the main body and continue their close association with their Trusts.

We believe that the Strategic Health Authority which is responsible for the health services in a community would be the appropriate body to appoint members and to fund LINks.

Areas of focus

The welfare of patients and the public, including those with special needs.

Statutory powers

To inspect all premises providing NHS care (including private hospitals with Trust contracts) and to submit reports to the appropriate Trust. The Trust must respond to recommendations within a specified time as under the present system.
Relations with local health Trusts

To expect full co-operation in respect of investigations, action on recommendations and to invite patient and public representatives to sit on their Committees as appropriate.

National coordination

There needs to be at least a regional, if not a national co-ordinating body. We believe that Strategic Health Authorities should be involved at regional level.

*How should LINks relate to and avoid overlap with:*  
Local Authority structures including Overview and Scrutiny Committee

Submit reports to and receive reports from the OSC. Patient and public representatives should be invited to sit on the Committees.

Foundation Trust boards and Members Councils

Inspectorates including the Healthcare Commission

To receive its reports and act on deficiencies highlighted.

Formal and informal complaints procedures

To receive regular reports from PALS, ICAS and any others to indicate deficiencies which need to be investigated.

*In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?*

- We believe that the SHA is the appropriate body to instigate wider consultation, perhaps advised by Patient and Public Involvement bodies

*Alex Nunes*
Chair

*Dr Michael Essex-Lopresti*
Secretary

Barnet and Chase Farm PPI Forum

15 December 2006

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**Evidence submitted by BLISS (PPI 9)**

**Introduction**

BLISS, the premature baby charity, is dedicated to making sure that more babies born prematurely or sick in the UK survive and that each one has the best quality of life. BLISS aims to realise this by:

- supporting parents and families;
- promoting new developments and innovations in care; and
- campaigning for improvements in neonatal care.

We welcome the opportunity to respond to this consultation and we will make a number of points regarding the particular circumstances of patient involvement in neonatal care.

We have been the leading charity working for sick and premature babies for over 25 years. A major part of our work is the provision of support to parents and carers such as a telephone helpline, publications on specific issues when caring for sick and premature babies, online information and a website message board.

In addition to our board of trustees, our work is informed and monitored by a Nursing Advisory committee, a Medical Advisory committee and a Parent Advisory committee.
1. **What is the purpose of patient and public involvement?**

1. For neonatal services to be responsive to the needs of parents and babies, parents should be involved in making decisions about the type of service delivered. If parents are given the support, care and facilities that they need within a particular neonatal unit, it can impact on their wellbeing—physically and emotionally, which in turn can impact on their baby’s health. We believe that parents can influence neonatal services in a positive way and that this will result in reduced neonatal and infant mortality and better long term outcomes for babies born sick or premature.

2. **What form of patient and public involvement is desirable, practical and offers good value for money?**

2.1 There are particular problems in ensuring that neonatal services are included within mainstream patient and public involvement programmes. This is for a number of reasons including:

—— Neonatal intensive care is a designated a specialised service, while special care is not and therefore different commissioning arrangements apply.

—— Although around one in eight babies are admitted to hospital for some time after they are born, neonatal care remains a “minority” healthcare area and is often neglected in more mainstream discussions about maternity services.

—— Having a baby in neonatal care can be an extremely stressful experience for parents and it might be difficult for parents to revisit that experience within discussions with other healthcare areas.

—— As parents and carers with young children, who might be in full-time employment, it can be difficult for parents to find time to attend meetings and read papers.

2.2 Therefore to ensure that the voices of parents are fully heard within neonatal care, BLISS is running a programme of user involvement. The introduction of managed clinical neonatal networks run by boards in 2003 has provided an opportunity to involve parents in the planning of neonatal care. Network boards are made up of health professionals (both doctors and nurses), managers, representatives from Primary Care Trusts, commissioners and should seek patient involvement. The aim of the BLISS programme is to recruit, train and support parent representatives on neonatal network boards.

2.3 The programme is currently in the second year and is designed as a three year programme. In the first year, funding was received from the Care Services Improvement Partnership. The objectives of the programme are to:

—— Recruit parent representatives to interested neonatal network boards in England.

—— Ensure our parents representatives on the network boards receive training from BLISS by March 2008.

2.4 This project has already achieved the following:

—— An information pack and application procedure for parents who are considering sitting on neonatal network boards.

—— A briefing pack for parents who have been recruited to network boards.

—— An area on the BLISS website message board to allow parents to network with each other and provide peer support.

—— Parent representatives receive regular bulletins and updates from BLISS.

—— Network boards cover the cost of child care as part of routine expenses.

—— A total of 18 parent representatives spread across eight networks.

—— A pilot training day for all parent representatives has been held with more sessions for two different networks planned for 2007.

—— An independent evaluation has been started by the University of Warwick to look at the effectiveness of parents represented on the boards.

Work is under way aiming to:

—— Develop a suggested induction programme for all representatives to be disseminated to all network boards.

—— Develop training for network boards on how to maximise participation from parent representatives.

—— Draft and disseminate a protocol of best practice for involving parent representatives to all network boards.

2.5 The first stage of the programme has been a pilot exercise of parent recruitment to the three neonatal networks in the Midlands (South West Midlands, Central Newborn and Staffordshire, Shropshire and the Black Country). An evaluation is being carried out by the University of Warwick, looking at both the pilot area and two other “case studies” nationally. Early indications show that while there are some barriers to overcome in terms of the “bureaucratic” nature of meetings, the BLISS user involvement programme is bringing consider benefits. Some of the positive aspects include:
— Generating a sense of pride in “our” NHS.
— Parents being consulted on issues of importance in neonatal care.
— Assistance with developing communication materials for parents.

Further research will be undertaken by the University of Warwick and the findings will be disseminated nationally.

2.6 BLISS would recommend that the principles of our user involvement project are extended to other healthcare areas and to other aspects of health policy, such as commissioning. It is important to find a mechanism where smaller healthcare areas such as neonatal care are given fair representation. There are a number of proposals in the Department’s Health’s document Health Reform in England: update and commissioning framework, published in July 2006 regarding community action. If petitions are going to be introduced in order to trigger community action by Primary Care Trusts then a device should be found which is not dependent on patient numbers to allow specialised services to be included. Specialised services should not be further marginalised because of the small volumes of patients using the service. In fact it is even more important to include specialised services as BLISS has found in relation to neonatal care it can be difficult gain a review of a specialised service by an independent body such as the Healthcare Commission.

2.7 Even within the small numbers of specialised services, there may be minority issues that are important but low in volume and the needs of these parents need to be equally represented. There should be a balance between public opinion and the complexity of the service. One way to do this might be also to allow parent representatives on network boards to be able to raise issues of concern and feed in to the formal community action process.

Emily Robinson
Campaigns and Policy Manager, BLISS
19 December 2006

Evidence submitted by Breakthrough Breast Cancer (PPI 42)

1. INTRODUCTION

1.1 Breakthrough Breast Cancer is the UK’s leading breast cancer charity and is committed to fighting breast cancer through research and education. Breakthrough has established the UK’s first dedicated breast cancer research centre, in order to obtain our vision: a future free from the fear of breast cancer. Breakthrough campaigns for policies that support breast cancer research and improved services, as well as promoting breast cancer education and awareness amongst the general public, policy makers, health professionals and the media.

1.2 Our memorandum reflects the views of Breakthrough and members of its Campaigns & Advocacy Network (Breakthrough CAN)—which is made up of 657 individuals and 97 organisations. Many members of Breakthrough CAN have personal experience of breast cancer as well as being involved in and working alongside their local NHS to try to deliver better treatments and services for people affected by breast cancer and their families.

1.3 Breakthrough welcomes the Health Committee’s inquiry into Patient and Public Involvement in the NHS. Breakthrough believes that in order to ensure a truly patient-led service, it is essential that the systems and structures are robust and meaningful so that the patient voice is heard at all levels of planning, commissioning, delivery and evaluation of health and social care.

1.4 Breakthrough welcomes the Government’s commitment to establish an effective Public and Patient Involvement in health system. This policy and practice should be one of the key vehicles the Government uses to make its vision of a patient-centred NHS a reality. Breakthrough staff and CAN members would be willing to provide oral evidence to this inquiry, if the committee would find this useful.

2. What is the purpose of patient and public involvement?

2.1 Breakthrough Breast Cancer believes the purpose of patient and public involvement is to enable the patient and publics to help shape local healthcare services so that they truly reflect the needs of the population they serve. It is important that patient and public involvement structures do not simply become another means by which a complaint about local services can be raised.

2.2 It is important to get both patients and the public involved as they may have different health priorities, all of which should inform the design of local healthcare services.

2.3 It is very important that patients and the public have a stronger voice at a national as well as a local level and the Government should ensure that the National Voices project considers carefully how best to harness the expertise of any new, local initiatives designed to involve patients and the public.
3. **What form of patient and public involvement is desirable, practical and offers good value for money?**

3.1 Breakthrough Breast Cancer would like to see forms of Patient and Public Involvement that are well planned, structured, staffed and resourced.

3.2 Some Breakthrough CAN members involved in Patient and Public Involvement Forums have told us that the protocol and bureaucracy involved in moving their work plans forward left them feeling disillusioned and frustrated:

> “I wanted to provide some information to the South West Breast Screening Quality Assurance Reference Centre from our Patient and Public Involvement Forum on our headed notepaper and found the procedure of meetings and committees involved in getting a simple information request approved very frustrating.”

Quote from Breakthrough CAN member, Cornwall

3.3 Patient and public involvement should be part of a simple and streamlined decision-making and change-effecting process.

3.4 The constant change and reform of patient and public involvement in health structures has also left many of those involved feeling disillusioned and frustrated. It is now important for the Government to put in place a system that is effective and given time to “bed down”.

3.5 Patient and public involvement systems and structures should enable patients, the public, health care professionals and other stakeholders to formulate a shared agenda to improve patient services.

3.6 One example of how Patient and Public Involvement can directly lead to tangible improvements in service delivery is Breakthrough’s *Service Pledge*. This project, initially piloted in 2003 and now involving 10 breast units throughout England and Wales, enables staff and patients to work in partnership towards a patient-centred breast service. Beginning with patient questionnaires and patient interviews carried out by trained members of Breakthrough CAN, the *Service Pledge* asks patients to speak up about what matters most to them. This often differs to what staff may assume is a patient priority. For instance, patients may simply want seating to enable them to chat to one another in the waiting room.

3.7 Examples of improvement goals to date include a photographic guide to surgery results, a waiting-times board that communicates to patients the cause of delays and a community drop-in service for patients in a rural area.

3.8 The end product of the project is a *Service Pledge* leaflet, produced by each breast unit taking part, which publicises to all patients the existing service available and also a minimum of three patient-led improvement goals. A generic *Service Pledge* is enclosed.

4. **How should LINks be designed?**

4.1 As well as providing opportunity for those already involved in Patient and Public Involvement, it is important to attract a wide diversity of people to get involved in the new LINks. This will require new and innovative ways to get people involved so that the membership of LINks truly reflects the make-up of the population they will serve.

4.2 There should be a clear means by which the new LINks are able to access the views of patients and the public, as well as a means by which matters can be raised with the new LINks. Where LINks wish to involve an adviser for a particular review of breast cancer services, they should be encouraged to contact patient advocacy groups such as Breakthrough CAN.

4.3 It is important to remember that those involved in patient and public involvement are usually volunteers who often have busy lives. The new networks should be made flexible enough for people to get involved as much or as little as they would like depending on their circumstances.

4.4 Through supporting and training members to become patient advocates in their own right, Breakthrough CAN aims to increase the influence of patients and the public in decisions regarding all breast cancer and wider health issues. Similarly, members of the new LINks, especially those with language, learning or transport difficulties, should be provided with adequate training and resources to support their role.

4.5 It is important that LINks work closely with local authorities to help shape healthcare provision for the local community. This relationship should be characterised by transparency and accountability.

4.6 LINks should be mindful of their need to focus on less obvious issues that affect patients, like access to complementary therapies, welfare benefits, costs of travel for patients and the promotion of local NHS services.
5. **Wider public consultation and Section 11 of the Health & Social Care Act**

5.1 Breakthrough welcomes the opportunity for local people to be engaged in discussions around the changes to local NHS services.

5.2 A number of Breakthrough CAN members have told us that NHS Trusts are failing to engage with local people about changes to local NHS services. They have told us that their Trusts are not pro-actively telling the public about proposed changes and seeking their views.

“I feel strongly that the Royal Cornwall Hospital Trust did not fully engage in a proper consultation process with regards to the recent and ongoing reconfiguration of local services. The local Patient and Public Involvement Forum served a Section 11 notice on the Trust as well as the Local Authority Overview and Scrutiny Committee but it was not acted upon and no formal explanation as to why not was provided.”

Quote from Breakthrough CAN member, Cornwall, who felt that by the time consultation was introduced the real decisions had already been taken.6

“I feel strongly that the consultation on the Bristol Health Services Plan, with implications for local breast care services, was carried out without any real effort to engage with local people. Only six people commented on the proposals for breast care services. Test Research, part of Mori, did a telephone survey of 654 adults in Nov 2004 and discovered that only 20% were aware of proposals for breast services.”7

Quote from Breakthrough CAN member, Bristol.

6. **Recommendations for Action**

6.1 The Department of Health should commit to maintaining a workable system for patient and public involvement in the long term rather than the short term. There is a real danger of patients and the public losing enthusiasm for the principle of user involvement if the systems are constantly changed and poorly communicated. Patients Forums were in existence for only three years before it was decided that they needed to be changed. Such changes may be necessary for the long term future of patient and public involvement but can be unsettling for staff and volunteers involved in the system and many Breakthrough CAN members feel that the new changes need to be given due time to “bed down”.

6.2 The Department of Health should review the current roles and responsibilities of stakeholders including the Healthcare Commission, Local Authority Overview and Scrutiny Committees, Independent Complaints Advisory Service, the new NHS Centre for Involvement and Foundation, Trust boards and members councils as well as all NHS Trusts in light of the proposed new LINks. This is necessary in order to clearly define their roles and responsibilities, and their relationship to each other.

6.3 It is important that the Department of Health considers how the role of the new LINks will develop alongside other existing and proposed initiatives designed to involve users and share best practice where applicable. Cancer Network Partnership Groups, Patient Advice and Liaison Services, peer review, community petitions, patient choice, the National Voices project and the new NHS Centre for Involvement are all examples of where LINks could and should have strong working relationships to avoid duplication, co-ordinate work and identify where they can add value to each other. It is also important that the work of LINks is joined-up with broader Government initiatives where they could add value, like the Government drive for Third Sector involvement in public services.

6.4 Breakthrough Breast Cancer welcomes the Government’s efforts to empower Local Authority Overview and Scrutiny Committees but in addition, every effort must be made to ensure that those committees are working effectively with local NHS Trusts and the new LINks to shape and deliver improved healthcare locally. Some Breakthrough CAN members have raised concerns that Overview and Scrutiny Committees do not currently operate as an effective check and balance on NHS Trusts because the Committees are perceived as not being independent from NHS Trusts.

6.5 Breakthrough CAN members have told us that the effectiveness of Patient and Public Involvement Forums varies across the country. Breakthrough recognises efforts to ensure that the new LINks are flexible but recommends that basic expectations and core standards of engagement should be established to ensure a level of consistency across the country.

6.6 There should be an annual evaluation of LINks and any common themes in terms of the patient experience should demonstrably feed into new Department of Health initiatives to improve the experience of patients. This evaluation could be incorporated into the Healthcare Commission’s Annual Health Check, although it is important that the Healthcare Commission seeks concrete examples of meaningful engagement with LINks from Trusts, rather than asking them simply to tick boxes to confirm that they have consulted with them.

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6 The Department of Health publication *Keeping the NHS Local: A new direction of travel*, specifies that options for change must be developed “with people, not for them” right from the outset, “before minds are made up”.

7 As stated previously, Breakthrough CAN members would be willing to provide oral evidence to this inquiry, if the committee would find this useful.
6.7 The Department of Health should consider reviewing how Section 11 has worked in practice, by approaching NHS Trusts, patients and the public that have been involved, as well as the Healthcare Commission. The wording used in Section 11, “substantive change to patient care”, needs clarification. The Department of Health might wish to consider issuing guidance supporting the operation of Section 11 in practice and good practice examples of Trusts that have actively engaged with the public should be shared. Thought should also be given as to how the new LINks will fit into ensuring that Section 11 works effectively.

Vicki Nash
Breakthrough Breast Cancer
8 January 2007

Evidence submitted by Bristol PCT PPI Forum, United Bristol Hospitals NHS Trust PPI Forum and North Bristol NHS Trust PPI Forum (PPI 63)

1. INTRODUCTION TO THE SUBMITTERS

The Submitters are the elected Chairs of statutory Public and Patient Involvement Forums for NHS Trusts and Primary Care Trusts in the Bristol area. In this area (formerly covered by the old Avon Health Authority and Avon County Council), separate health economies centred on the Unitary Authorities created in 1996 are still closely interconnected by geography, history and health services configurations which have evolved over many decades. This interconnection and the mutual dependencies are currently recognised by the involvement of local NHS bodies, and their corresponding PPI Forums, in the Bristol Health Services Plan—a sweeping plan to rationalise and modernise NHS services for the population of the whole area.

2. COMMENTS ON THE THEMES OF THE SELECT COMMITTEE’S TERMS OF REFERENCE

What is the purpose of patient and public involvement?

We believe that this is to ensure that the views and experience of patients and the public are taken into account alongside those of NHS professionals when important decisions about NHS services are being made.

3. What form of patient and public involvement is desirable, practical, and offers good value for money?

3.1 It is critical that PPI should operate not just on a passive consultational level, but that it should be at the heart of policy formulation and decision making. Too often, it has taken the form of seeking opinions on a small number of pre-established options for change. Representatives of the public should have real influence in the whole process, from the recognition and formulation of the need for change through to the practical decisions for implementation and monitoring. Finding the logistics and structural arrangements to allow this are the greatest challenge faced, and the governance arrangements and the membership structure of LINks are problems that we do not feel have been given any productive thought in the documentation we have so far seen. When these central issues were raised with representatives of the DoH at a recent conference for stakeholders in the future LINks, it was openly admitted by them that no clear solutions were in sight.

3.2 It also seems very clear that the current arrangements for PPI through Forums have been grossly under-funded, and thus under-resourced. This seems to be a universal perception amongst all involved in PPI Forums. Much of the criticism levelled at CPPIH flows from its inability to direct adequate resources to support Forums, and one small example of this has been the blanket ban on paid advertisements in the local press to publicise Forum meetings, and facilitate public presence and input to Members’ consideration of local health issues. The criticism from government that Forums have not been good at involving local people seems highly disingenuous given this basic government-imposed handicap. We fear, listening to the well-sourced rumours that funding will not be increased, and considering the refusal to ring-fence funding going to Local Authorities for LINks, that the severe under-resourcing of PPI structures will continue when LINks take over these responsibilities.

4. Why are existing systems for patient and public involvement being reformed after only three years?

4.1 Why indeed? It was apparently not the legislation, but the political will and commitment that was lacking. Barely six months after PPI Forums were created, the Government announced the abolition (less than 18 months after its own creation) of their parent body the Commission for Public and Patient Involvement in Health. Despite the uncertainty since then over the exact future shape of Forums, until

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8 For example, Liverpool PCT’s Big Health debate.
comparatively recently, the messages coming from government insisted that Forums remained the future vehicle for PPI. The proposals for LINks did not appear until July 2006, and there had been no prior indication of the drastic changes now being implemented. It is true that NHS policy initiatives such as Foundation Trusts, Payment by Results and Patient Choice are changing the stakeholder landscape, but none of these has appeared without warning in the last year. Any arguments that “PPI Forums are just not working” must have been apparent to policy-makers at the very time they were giving assurances that the future for PPI lay with Forums. There is a strong impression that PPI has been used as a “political football” since January 2003. The response given by CPPIH to the consultation on A Stronger Local Voice tells the story of funding promises broken and deadlines advanced to an impossible extent during its struggle to get the PPI Forums established and working effectively. Once again, Members of Forums smart with injustice under DoH criticisms that the new arrangements have not lived up to expectations: how could they, when those expectations were not matched by the essential political and resource commitments?

4.2 We feel strongly that PPI Forums have not been allowed to develop to their full potential. Even so, one of our largest local acute Trusts so values its Forum’s work that it has asked it to continue this work when its statutory existence is ended, with equivalent powers granted by the Trust to replace those lost when the legislation is changed. This Trust has developed an excellent working relationship with the Forum, and the Board routinely considers reports by the Forum on its services and formulates action plans to implement appropriate measures in response to their findings.

4.3 Another example of the success of local PPI Forums is the excellent working relationship that they have developed with the Local Authority Overview and Scrutiny Committees covering the Bristol area. Forums have co-opted membership or other representation arrangements at all these OSCs, and they have been described by one as the OSC’s “eyes and ears”. A number of joint training and working sessions have been held, and a joint data-base of workplans has been set up to coordinate activity. Forums regularly present their service review reports to the OSCs, and these are always well received, with officers of the relevant NHS organisations being called by the OSC to address concerns raised in the reports. In addition, officers of the Forums, of OSCs and of local NHS organisations meet regularly to discuss work and developments.

4.4 We have heard the Department’s argument that PPI through Forums is not working, but these examples (and there will be many others across the country) proves that the present system can and will work. The establishment and “testing” of these local relationships has taken time, and it is ironic that their statutory basis is being removed just when their value is becoming clear.

5. How should Local Involvement Networks be designed?

5.1 Our feeling is that the development of thinking on LINks is being driven by conceptual ideals, with insufficient attention to the practicalities of how they will work. Given the stage of development of the move towards LINks, and the commitment given to legislation in the Local Government and Public Involvement in Health Bill, we find this lack of practical detail very worrying.

5.2 We know from experience that Forums’ success depends on effective organisation and administrative support. Although we know little in detail about LINks at present, we have been told that they will have very large numbers of participants—estimates have swung between “hundreds” and “thousands” per LINk. Communication and coordination alone will be huge undertakings, and the wider administrative needs will make support of these bodies a massive task. The Government response to consultation suggests the governance model of a “Stewardship Board”; and the suggested responsibilities of such a Board (page 20 of the Response) include the accountability for and management of a budget, work planning, membership and governance issues, direction of Host staff, commissioning of external work, performance management, coordination with a wider membership—all this on top of the work of involvement that will be the LINks true task.

5.3 A major gap in the detail we have seen so far, is the manner in which LINks will be held accountable and by whom. This question has been raised by delegates at a recent DoH conference on LINks, where it was met with a shrug of official shoulders, and a request for any suggestions from the delegates. Eventually, the answer was proposed that LINks will be accountable to the populations of the PCT areas that they represent. No explanation could be given of any mechanism by which this might work, and the DoH representatives seemed completely wrong-footed by this very obvious and central question. We feel that this is a major area of concern.

5.4 The Select Committee’s Terms of Reference pose a number of specific questions on the nature of LINks, and we will address some of these:

(i) Remit and level of independence—we would see the level of independence currently achieved through an arms-length-body as being the minimum level of independence needed from both government Departments and from local government.

(ii) Membership and appointments—we welcome the fact that LINks would be able to determine their own membership.
(iii) **Funding and support**—we have already touched on this, and would stress that the resources provided to local authorities for the resourcing of LINks should be ring-fenced to that purpose, and should be adequate for the wide range of activity envisaged and for the essential publicity and communication of LINks with their “constituencies”.

(iv) **Area of Focus**—We welcome the ability that LINks will have to operate on both sides of the boundary between health and social services, and recognise the strength of the government’s arguments for this.

(v) **Statutory powers**—we think it is essential that LINks should inherit the powers to require information and to visit NHS premises currently exercised by PPI Forums.

(vi) **National Coordination**—It is important that there should be some mechanism for communication between LINks, and we think that the issue of “ownership” of any such arrangements might become important. There will always be the fear locally that any such national arrangement might become a mechanism for “managing” LINks, and be subject to influence from government departments.

(vii) **Relationships and overlaps**—We wish to stress the importance of a public voice for PPI that is independent of the political agendas of the NHS and local government. On their visits, PPI Forum members have been struck by the comments of patients that they value a non-intimidating ear for their comments. Frequently, members have had the experience during their inspection visits of being approached by patients a second time after NHS staff have left, and hearing a different story to that originally told in front of those staff. We do not blame the staff for this: it is human nature that no one wishes to offend those who are caring for them. It does, however, illustrate how important perceived independence is in gaining the views of patients and the public. The Healthcare Commission has also recognised the importance of PPI Forums’ contributions to its NHS bodies self-assessment process, and would no doubt find the participation of LINks equally valuable. Far from worrying about any overlap, the Commission has said that the Forums’ comments as part of the self assessment process has had a major impact on the process for validation of the self assessments of some NHS bodies.

6. **Recommendations for Action to the Government**

   — Maintain Forums’ independence and statutory powers.
   
   — Provide realistically adequate funding, ring-fence the funds, and ensure that there is provision within this funding for proper publicity and communication with the public.
   
   — Clearly define the structures, responsibilities, and governance arrangements of the new PPI organisations. Do not pass the buck by expecting each LINks to devise its own.
   
   — Don’t rush it. If this system is less successful than the last, you will lose the good will of volunteers, and LINks will collapse.

*Bob Maggs*
Chair
Bristol PCT PPI Forum

*Penny Robinson*
Chair
United Bristol Hospitals NHS Trust PPI Forum

*Chris Windows*
Chair
North Bristol NHS Trust PPI Forum

9 January 2007

**Evidence submitted by the British Medical Association’s Patient Liaison Group (PPI 148)**

**Executive Summary**

The majority of people want a say in how local healthcare services are run but, more often than not, have never been asked about what they would like from their local services. In addition they feel that they have no power to influence local service development.

Continued interference by government with formal structures of PPI has damaged their effectiveness, with the naivety of the LINks proposal being an illustration in point. It is clear that the authors of government proposals and legislation do not understand how meaningful patient and public participation and involvement work.
The key is resources and capacity. PPI needs to be properly funded to enable whatever the organisational structure for PPI is at the time to be able to consult with the community it serves. This means engaging with service users, taxpayers and groups who traditionally do not, or cannot, get involved.

Capacity for meaningful engagement is a rare commodity. The government’s response to A Stronger Local Voice barely recognises the imperative to provide administrative and financial support to members of LINks if they are to be effective. There are few people who have the capacity to really engage, and to find ways of engaging others. Capacity is about having time, self-confidence, access to technology, the ability to spend hours reading lengthy and often turgid official documents, political skills, committee experience and the availability to attend meetings during working hours as well as outside them. Those that do have the capacity should be supported.

It is not the case that most people do not have the intellectual ability to participate because it is clear that they do. People can make rational and reasoned decisions about complex matters when given the information and time to do so. (The two case studies given in this response are examples in point.) Too few ordinary members of the public have this capacity, and much more should be done to build it. Without building capacity, LINks will go the same way as their predecessors because they are fundamentally flawed.

PPI does not need to be prescriptive about methodology, but should consider a number of principles to underpin such processes, including that:

— it should be a collaborative process with all voices in discussion helping to develop partnerships between patients, the public, health professionals and policy makers;
— the process should be ongoing and not just a periodical or one-off exercise;
— feedback mechanisms must be built into all PPI activities;
— the processes must be transparent;
— PPI activities must be accessible to all relevant groups; and
— efforts must be made to specifically target hard-to-reach and marginalised groups in order to accommodate equality and equity within the PPI structures and the relevant health services.

ABOUT THE BMA

1. The British Medical Association is an independent trade union and voluntary professional association which represents doctors from all branches of medicine all over the UK. It has a total membership of over 138,000.

2. The evidence for this select committee inquiry was compiled by the BMA Patient Liaison Group and endorsed by the BMA. The Patient Liaison Group consists of 11 lay members appointed for their knowledge and interest in different aspects of healthcare, and five doctor members. The lay members do not represent any particular patient group, but bring a wide overview and knowledge of health issues to their discussions.

IN RESPONSE TO THE INQUIRY’S QUESTIONS

Q. What is the purpose of patient and public involvement?

3. The public is concerned about the future of Britain’s public services with more than half (57%) thinking that government policies will make public services worse. In health, almost half (46%) think that the NHS will get worse over the next few years. Only one in five (19%) thinks that present government policies will make the NHS better.¹

4. A recent survey found that the vast majority (90%) of those asked agreed that local people should have a say in how local healthcare services are run, with three-quarters (74%) wanting a say in how their GP surgery and local hospital are run. However, the same survey found that three-quarters (76%) of people had never been asked about what they would like from their local services, and half (50%) felt they had no power to influence service development in their area.²

5. The public has had its expectations of the NHS vastly raised as a result of investment and of the government telling people that they can expect more and offering a more consumerist approach to healthcare. Choose and Book is an example of this, where patients can literally vote with their feet by choosing where they want their care delivered. Choice in principle is good, and wanted, but it needs to be properly informed. Words such as “empowerment”, “a need for voice” and “patient-centred” are used, but need defining and given greater meaning. At present, the only choice is a choice of hospital.

6. At present, policy on patient choice risks worsening inequalities in healthcare. Wealthy and educated populations will be the main beneficiaries. The rise of consumerism and the introduction of markets have created additional drivers for choice. There is no evidence that increasing patient choice will, of itself, improve the quality of patient care. Indeed, some studies suggest that increasing choice may result in a deterioration in the quality and cost-effectiveness of services.³ The aim of choice should be in empowering patients, improving outcomes and contributing to reducing inequity.⁴
7. How far patients behave as consumers is suggested in a recent briefing paper to depend on the severity of their illness, the nature of the procedure involved and their individual circumstances. As both the severity of the illness and complexity of the process increase, so patients refer more decision-making to a well-informed and trusted health professional. The limited choice so far offered—a choice of hospital—is only of relevance where there would otherwise be a long wait for treatment, or where there is a history of poor service. GPs are often unable to recommend a consultant at a distant hospital whom they do not know, so the patient may be making an unsupported decision.

8. This emphasis on choice means that future services could be based on individual referral decisions. There needs to be a balance between the individual as a consumer, using services, and as a citizen, playing a part in how services should be delivered: a balance between choice and voice.

9. It should not be forgotten that choice in healthcare is not a choice most people want to make. It is not a pleasurable choice, and the choice for most would be to be completely well and not to need the health service at all. What patients want is good quality treatment and care, delivered close to home, by a professional team that they trust. In turn, doctors and other healthcare professionals want the resources and autonomy to be able to deliver that care.

Why public involvement is necessary for all public services

10. Simply put, there is a democratic deficit. It should be a fundamental tenet of organisations that those paying for a service and those affected by it have a right to be engaged in its design and development. One problem with public involvement is that it is, at present, too often merely placatory.

11. Public involvement should be necessary for decisions as to what services are provided, how they are provided, quality setting, and monitoring and the maintenance of standards. A service can only be responsive to users if users are involved. Public involvement offers service providers and commissioners the opportunity to better understand the needs of the public.

12. Public involvement has never been more important than it is now, at a time of reconfiguration and when crucial decisions are being made by commissioners which impact on local services. If providers are to purchase services on behalf of taxpayers it makes sense that commissioners talk to them about the services they buy and forge relationships with them so as to increase their knowledge about the quality of the services for which they pay.

13. Reconfiguration will involve difficult decisions that it is important to get right. In the context of limited resources, the service needs to consult with the public to identify what they need rather than what they want.

Patient and public involvement in healthcare services

14. The concept of PPI in health is not new. It has been considered a worthwhile aim by successive governments, and professional organisations and regulators make use of patient input and recognise its importance.

15. The term patient and public involvement encapsulates the two streams of lay involvement in healthcare services. Patient involvement is the contribution of individuals to their own healthcare, and public involvement the participation of individuals or groups in the development, planning and provision of services.

Legal responsibilities to the patient and publics

16. In the 1990s the NHS patients’ charter focused on operational items such as waiting times rather than the principles of the service. It was found that few patients were aware of the details of the charter, that it was rarely utilised and that it did not balance raised expectations with patient engagement.

17. With patient rights should also come patient responsibility. The patients’ charter was a rights-only charter, with no mention of responsibilities. The majority of patients accept and acknowledge their responsibilities, including making appropriate use of services, behaving in a civil way and co-operating in their own healthcare. There are current examples of where patients’ charters are used, including Hong Kong, Spain and King’s College Health Centre in London. Each of these examples emphasises both the rights and the responsibilities of patients, reflecting the partnerships that are necessary within healthcare. The concept of a patients’ charter based on these rights and responsibilities would be supported.

18. Section 11 of the Health and Social Care Act of 2001 (now Section 242 of the NHS Act 2006), made public consultation a legal requirement at the level of Primary Care Trusts (PCTs), Strategic Health Authorities (SHAs) and NHS Trusts with regard to:
   — the planning and provision of local services;
   — the development and consideration of proposals for changes to the way services are provided; and
   — decisions that will affect the operation of services.
19. The government has been pushing forward with current reforms under the justification of ensuring a patient-led NHS. Even with Section 11, there is no coherent guidance as to how effective participation can and should be achieved and some organisations have struggled to comply with this requirement. As yet, the necessary honesty and balance about the evidence or motives behind reform plans has often been absent.

20. In December 2006 the *Local Government and Public Involvement Bill* was introduced into the Commons. This aims to formalise, in legislation, the link between service providers, including local authorities, and local involvement networks at the level of local authorities. The bodies involved, Local Involvement Networks and Overview and Scrutiny Committees, are discussed below.

**Patient and public involvement in healthcare**

21. There is often a disconnection between what people are told needs to be done, for example closing an A&E department, and what the public actually believes should be done. Effective PPI is a benefit to people and organisations because it allows them the opportunity to engage in decisions about healthcare services, and because it can:

- educate the patient and public body;
- allow the public to see what good has been done and recognise what improvements have been made; and
- allow the public to understand what constraints there are.

22. Healthcare policy decisions, at whatever level they are made, ultimately affect patients’ lives. Therefore it can be argued that patients have a moral and ethical right to play a meaningful role in developing healthcare policies. Engaging patients in health policy decision-making helps to ensure that policies reflect patient needs and preferences, and this must ultimately make for more effective healthcare. In a publicly funded health service, this serves to increase accountability.

23. PPI is not about people wanting to make the clinical decisions. It is, in part, about facilitating patient autonomy and, together with clinical autonomy, holding managers to account. Getting the public involved will not happen through good intentions; it requires commitment, resources and building capacity for involvement to happen and be effective.

24. Healthcare professionals and patients should foster partnerships, leading to more effective care. Patients want to be involved in decisions about their healthcare and treated as partners by health professionals. They would often like to be offered a choice of treatment and be informed to enable them to make a choice. A collaborative approach to decisions improves outcomes as patients are more likely to comply with medication and treatment if they are involved.

25. In a market environment which has been created for providers to compete with one another for patients, PPI is not just necessary for NHS providers but also for private and third sector organisations commissioned to provide services financed by the public purse. This is particularly important in the context of care closer to home where policy decisions which cross the boundaries between healthcare and social care services have to consider quality, safety and equity.

**Q. What form of patient and public involvement is desirable and offers good value for money?**

26. Involving the patient and publics is not straightforward. People as individuals and as members of groups can have diametrically opposed views. Commonly excluded groups such as those with language difficulties, learning difficulties, physical disabilities, mental health problems and those without the time available to commit through traditional means of involvement need to be reached. Once involved, it is important that people do not become distrustful of the process. This can happen if their participation is not acknowledged, or when their contribution does not appear to make a difference or at least be considered. Involvement must not be tokenistic or not properly thought through.

**CASE STUDY 1**

*Thames Reach Bondway project to gain the views of homeless people in relation to their health and the services provided for them*

Thames Reach Bondway undertook a project in Lambeth to gain the opinions and views from homeless people in relation to healthcare.

The process involved recruiting a cross-section of people with a background in homelessness, representing a variety of homelessness experiences, health needs, gender, ethnicity and sexuality, and inducting and supporting them to facilitate focus groups and interviews with homeless people in hostels and day centres.

The facilitators interviewed groups of homeless people on GP services, hospital services and specialist services. They were asked to think about the services they had used, whether they were good or not and the reasons for that assessment. The outcomes of the interviews were compiled.
Several services were found to be good: GP services and hospital care where there had been long-standing relationships, hostels and day centres, and the Stockwell Drug Project. Several services were seen as not very good: services used by refugee/asylum seekers where there were communication difficulties, and A&E.

The impact of the project led the Guy’s and St Thomas’s Charitable Foundation to address access to A&E, the out-of-ours service and hospital care, and importantly to the opportunity for homeless people to develop skills and be able to present their views for consideration and discussion.

27. Public engagement must be more than a “tick-box” exercise. PPI structures should exist at all levels throughout the healthcare system, be properly resourced and should be used to feed both up and down into decisions relating to the design and development and the commissioning of services. Decision-makers should also be required to demonstrate how they have incorporated and responded to the views of those with whom they consulted.

28. A Which? Report identified that the main priorities for patients are that healthcare services are responsive to their needs and that they are delivered as close to them and as quickly as possible.27 The quality of healthcare, however, must not be compromised through working towards these aims and therefore the health and access needs of local populations must be identified. Such needs are affected by a combination of factors including the:

— geographical location—rural, suburban or urban;
— population demographics—age, sex, ethnicity, social-economic make-up;
— prevalence of long-term conditions;
— lifestyle behaviours—smoking and exercise rates, practicing safe-sex, diet and nutritional preference; and
— size of refugee populations and asylum seeker populations.27

CASE STUDY 2

Barnet PCT’s use of public involvement in steering commissioning decisions

Barnet PCT held an event in November 2006 to seek the views and opinions from members of the Barnet Council’s Citizens Panel and other stakeholders to help steer their commissioning decisions for 2007–08.

The PCT had allocated £60 million of uncommitted money for commissioning services and had shortlisted 24 interventions which participants could choose from on which to spend a portion of the pot. Examples of the interventions are:

— a better epilepsy service;
— cataract removal operations;
— increasing the smoking cessation service;
— one cycle of IVF; and
— greater access to digital hearing aids.

There were 56 participants arranged into roughly even groups at seven tables. Each table was allocated a facilitator and a note taker.

Some information about the interventions had been given out before the event, and on the evening itself the PCT Chief Executive, Medical Director and Director for Commissioning gave presentations on the background to the budget, the health of the local population and how services are commissioned.

Each participant was given eight tokens to allocate to interventions as they saw fit. There were provisos to ensure that there would be some “winners” and some “losers” amongst the interventions. There were two rounds of preference selection. During the rounds the facilitators asked participants to debate the interventions and give reasons for their decisions on how tokens were allocated.

At the end of the two rounds a simple mathematical model was used to transfer the “value” of the tokens to an overall preference score for each intervention. The highest scoring intervention was for funding extensions to GP surgery opening hours. Second and third on the list were maintaining current spending on hip replacements and reducing waiting times for hospital treatment. The exercise demonstrated that people, when given the opportunity, are capable of making rational and reasoned decisions.

The data will be taken into account by Barnet PCT when making commissioning decisions. The PCT has promised to feedback to those who took part and explain how the decisions made at the event influenced spending.

29. Guidance on engaging in PPI does not need to be prescriptive about methodology, but should consider a number of principles to underpin such processes, including that:

— it should be a collaborative process with all voices in discussion helping to develop partnerships between patients, the public, health professionals and policy makers;
— the process should be ongoing and not just a periodical or one-off exercise;
— feedback mechanisms must be built into all PPI activities;
— the processes must be transparent;
— PPI activities must be accessible to all relevant groups; and
— efforts must be made to specifically target hard-to-reach and marginalised groups in order to accommodate equality and equity within the PPI structures and the relevant health services.

30. Consideration also needs to be given as to where PPI is necessary. There are several layers of hierarchy in the health system which need to be held accountable, from the Secretary of State for Health through SHAs and hospital Trusts in secondary care, and PCTs and GP practices in primary care. The real power in these organisations follows the money; namely practice and trust based commissioning.

31. For the public to be truly engaged in the provision and delivery of services, it must be given the facts about costs, about how decisions are made in allocating resources, and about how money can be spent best to meet the needs of local people. PPI may not be high on the list of priorities for managers in the face of balancing the books, but its role, together with that of listening to the professionals charged with actually delivering healthcare, should not be underestimated.

32. Without proper involvement, people can unbalance arrangements through either action or inaction. Examples of action are where hard decisions need to be made, such as when the public react strongly to the closure of a service. Inaction where, for example, an initiative has not worked because managers with good intentions thought they were providing a service that people wanted, but they did not.

Capacity and representation

33. Capacity and representation will be a major concern for new initiatives in order to populate local networks enabling them to work for, serve and reflect their constituency effectively. Representation should reflect the population it serves to work towards ensuring that all views and voices are heard. Capacity is also necessary to ensure that the job of the representative group is done; that amongst the representative group there are people able to understand, communicate and, importantly, with the time to carry-out the complexities of the task in-hand.

34. Those responsible for consulting should seek to find what form of PPI is most effective for the purpose, significance and size of the task they are undertaking, but still with the principles set out above in mind. It is likely that a combination of methods will be needed.

35. Three different, but overlapping, patient voices have been identified, and each has their usefulness and limitations.14 These are:
— patients—they are experts in their own experiences and they can observe and reflect on those experiences, but may not know, for example, about the treatments or choice of drugs available to them;
— patient groups—they are expert in the views and experiences of patients like themselves; know what professional standards for treatment, for example, should be and can articulate them; know what common concerns their patients have; but can only cover a narrow band of expertise, in a specific disease area; and
— patient representatives/advocates—they have a general knowledge and hold the interests of all patients at heart; they can represent those interests; they study surveys and literature; they talk with patients and patient groups; but they may not know in detail about particular issues of any particular patient group.

36. A major problem in convincing organisations that PPI is worthwhile is: which voice should be listened to? The answer is that all voices should be given an opportunity to be heard. There are views that the naïve voice is the true voice, and that the voice of patient groups and advocates are that of the “usual suspects” or “self-appointed trouble makers”.

37. PPI should consider all individuals and groups as having good intentions and recognise the point of reference from where the voice comes. Where groups of patients are used to represent the “patient voice” it must be recognised that they cannot speak for the views of all patients, but that instead they speak for the values and interests of patients.14 These views can be triangulated with individual views through avenues such as a public meeting. A powerful tool is involving randomly-selected people. As well as improving the representation of views, it can help broaden the base for future consultation and encourage those who would not typically take an interest in local health to get involved.

38. Representation is required to ensure that all voices are heard and capacity is necessary to ensure that those voices are considered. Understanding and knowing how to work within the system is an important goal itself, for example, knowing who to contact and who to influence, as influences seem effective when relationships are developed with key people. Most groups who are successful in influencing change know who to talk to and understand the complexities and machinations of change.15
Q. Why are existing systems for patient and public involvement being reformed after only three years?

39. Whilst the standard of patient forums and the current system of local PPI, are variable, it is unclear as to why they and the Commission for Patient and Public Involvement in Health (CPPIH) are being discarded in favour of LINks. The criticism of patient forums is that, as well as their variability in quality, the cost of supporting them through CPPIH has been high. There is no reason to believe that LINks, as they are currently proposed, will be an improvement.

40. There are many different examples of mechanisms which can and are being used to engage the patient and publics in health reforms and decision making. Different methods will be appropriate in different settings and at different levels, whether that be for GP practices, Trust hospitals, medical schools or the Department of Health for example. Examples of PPI techniques include:

— public/community meetings;
— patient questionnaires or surveys;
— citizen’s juries;¹⁶
— election/selection to trust boards;
— PPI forums;
— patient liaison groups;
— consultation with disease specific/patient interest organisations;
— patient networks (often disease specific);
— practice level patient participation groups;
— patient champions; and
— electronically through, for example, www.patientopinion.org.uk or HealthSpace.

41. PPI happens now with varying effectiveness through:

— PPI Forums;
— general practice patient groups;
— consultations by PCTs, SHAs and Trusts; and
— government consultations.

Enlightened service providers, or elements within them, will use other forms of engaging with the patient and publics in designing and shaping services.

Foundation Trusts

42. NHS Foundation Trusts are part of the NHS reform programme built on the premise that because they are autonomous organisations free from central government control they can decide how to improve their healthcare services around local needs and priorities through establishing strong connections with their local communities. In addition, local people can become members and governors. Those living in communities served by a hospital of an NHS Foundation Trust are invited to become a member, and members can stand for and vote in elections for governors of the Trust. This form of public ownership and accountability aims to ensure that hospital services more accurately reflect the needs and expectations of local people.¹⁷

43. Foundation Trusts appear to be a failing area in terms of PPI, and there is a lack of evidence to show that they may be working. From experience, there is no consistency on how appointments are advertised or made. Lay governors are unsupported, usually receiving no training or administrative support, and their role in decision making is also negligible with decisions often being made by an executive group, with no lay membership, which are then in effect rubber-stamped by the board.

Other recent initiatives

44. Two recent initiatives, both supported and facilitated by the government, are aimed at professionalising PPI. These are the NHS Centre for Involvement and National Voices.

45. The NHS Centre for Involvement was launched on 28 November 2006 and focuses on services directed at health professionals to give them the tools to turn PPI into everyday practice. Amongst its core values and strategic objectives are the following:

— engage with local communities;
— develop responsive and democratically accountable services;
— promote the value of PPI;
— build capacity of organisations, staff and patient-citizens for high quality PPI; and
— generate evidence-based models of best practice.¹⁸
46. *National Voices* started as an independent group of health and social care related voluntary organisations looking at the decline in the public’s input into shaping national policy. It has now been asked by Ministers to explore how this can be done better. Its core aims are to:

- agree the principles that underpin the development of independent national voices of service users, patient and carers to influence strategy and policy across health and social care at the highest level; and
- investigate options to establish a mechanism that represents the independent national voices of service users, patient and carers.19

47. The values of the *NHS Centre for Involvement* and the aims of *National Voices* are all laudable, but professionalising of PPI may lead governments and providers to regard only the views of a national organisation or their locally trained patient advocates because they “represent the patient view”. This would be detrimental to PPI. People who do not belong to a patient organisation would not have a voice. Patient groups and charities who have worked hard to get their voice heard may lose that opportunity, and the “one” representative voice with, by its very nature, input from a myriad of views, will have difficulty putting together a coherent argument and will be easier for governments and providers to dismiss.

48. The White Paper *Our health, our care, our say* aimed to change the way community services are provided and give patients and service users more control over the treatment they receive.20 It identified a number of triggers, one of which is public petitions, to which PCTs would be expected to respond. Public petitions are envisaged as culminating in an arbitration procedure in making decisions about the provision of services.

49. As with other proposed initiatives there is no detail as to how petitions and the following process might work, with fundamentals needing clarification such as:

- who can petition;
- how many signatures would be required to trigger the process;
- what is the process for response;
- how the quasi-judicial process of arbitration would be set up or enforced; and
- how petitioners would be represented in the process.

50. There are also concerns with regard to whether or not the process is democratic. Getting a petition organised may lead to health inequalities as those very people who might most need one will be least qualified to organise it. A petition could be initiated by a local MP making it vulnerable to political manipulation.

51. If PPI is conducted and resourced properly, there should be no need for public petitions. Patients and the public should have proper accessible and democratic channels to go through without the need of getting up a petition.

Q. How should LINks be designed, including:

- remit and level of independence;
- membership and appointments;
- funding and support;
- areas of focus;
- statutory powers;
- relations with local health Trusts; and
- national coordination?

52. *A stronger local voice: a framework for creating a stronger local voice in the development of health and social care services* was published in July 2006 with the aim of providing a framework for individuals and communities to have a stronger voice in their local health and social services by ensuring that the “needs, preferences and involvement of local people, including those that are seldom heard, are central to the planning, development and delivery of health and social care services.”21 The paper sets-out plans for local involvement networks (LINks) to replace the current PPI Forums. There will be fewer LINks, one per local authority, than there are currently PPI Forums. These LINks will be used to inform local authority Overview and Scrutiny Committees (OSCs) on public views on health and social care services. This relationship has been confirmed in the *Local Government and Public Involvement Bill*.12

53. Many people want a greater say in the local health services. As the Minister suggests in *A stronger local voice*: “We are committed to empowering citizens to give them more confidence and more opportunities to influence public services in ways that are relevant and meaningful to them”.23 This is a worthy aim, but extremely difficult to do in practice, as witnessed by the huge number of social inclusion, social capital building, and regeneration initiatives that have been started by this and previous governments. Mechanisms
for actual empowerment are not given in the white paper, and while formal arrangements are made clearer in the Bill, there is no detail with regard to how empowerment should happen and how its effectiveness should be monitored and regulated.

54. The legislation charges local authorities to enter contractual arrangements to run their LINks, but the governance of LINks will be left to local arrangements. In addition, the membership of LINks will be set at local level with no national guidelines for type or number of members or funding for resources or training for members. There is then a danger of inequity of public involvement between local authorities.

55. There are a number of possible strengths and weaknesses of this system over the current system.

Strengths
  — the smaller number of organisations may mean more capable people for recruitment to LINks (rather than those spread between the current numerous PPI Forums);
  — LINks with populations that are well educated and able to dedicate time may work well;
  — LINks will have the power to refer matters to Overview and Scrutiny Committees; and
  — LINks will have the power to inspect providers’ premises.

Weaknesses
  — LINks with populations that are less well educated or less able to dedicate time may not work well;
  — there may be conflicting views within LINks because of the size of areas covered and the priorities of particular localities;
  — LINks may be too closely allied to local authorities to be independent of local politics and any conflicts of interest that may arise;
  — there is a danger of LINks being patronised, out-thought and manipulated by managers; and
  — the lack of national coordination for LINks does not formally enable sharing of information, ideas and good practice.

56. Representation, capacity and resources are key elements in enabling LINks to work. None of these have been addressed in any detail in the consultation process or the Bill. The task of collecting real public opinion can be complex and time-consuming, particularly if it is to be done properly. LINks must have the capacity and resources to be able to undertake their duties. Representation would ideally reflect the population, but more important will be the ability of LINks to reach all the constituent parts of its population served, including those traditionally excluded.

57. The BMA understands that between £100,000 and £150,000 per annum will be allocated through local authorities for each of the LINks. This is not much if translated into salaries for a minimum number of staff, expenses for members, office accommodation and running expenses, let alone money for undertaking surveys of public opinion. In addition, it is unclear whether money for LINks will be ring-fenced.

Overview and scrutiny committees

58. While LINks have the power to refer matters for consideration to OSCs, OSCs must use LINks to inform their work in reviewing local health and social care services. OSCs are the only way that NHS organisations can be held accountable locally. However, there are potentially a number of failings in the OSC system which could undermine its effectiveness, namely:
  — seats are filled only by local councillors;
  — seats do not have to reflect the political make-up of the council (ie the majority party may choose to fill all seats);
  — councillors may have no interest in health;
  — councils have no financial hold over health service providers; and
  — being charged with overseeing both health and social care may result in conflicts of interest and culture between health and social care concerns.

59. OSCs have no mandatory powers to change anything. If their recommendations are not acted upon they can refer the matter to the Secretary of State who can make a decision or refer to the Independent Reconfiguration panel. In addition, due to other responsibilities and the timing of meetings, OSCs can only be reactive to fast moving situations in health rather than be proactive.

60. The government released its reply to the A Stronger Local Voice consultation in December 2006. In opening the reply the Secretary of State for Health says “I believe that seeking people’s views on the services they use is essential to improving both those services and the experiences of the people who use them.” The key here is the aim only to “seek” public views rather than actively engage the public in participating and influencing decisions on the content of services or of the commissioning of services.
61. Overall, the arrangements between LINks, OSCs and health and social care providers appear extremely bureaucratic. If LINks are to have any real influence they will need much more funding than PPI Forums ever received.

Q. How should LINks relate to and avoid overlap with:

- Local Authority structures including Overview and Scrutiny Committees;
- Foundation Trust boards and Members Councils;
- Inspectorates including the Healthcare Commission; and
- formal and informal complaints procedures?

62. Concerns regarding local structures, Foundation Trusts and other bodies have been examined elsewhere in this response. The lack of coordination between bodies bring immediate concerns about patient safety and the quality of services, and they are inpenetrable as a group.

63. With regard to complaints procedures, there appears to be no intention to formally relate LINks to local systems, and local complaints systems have been found to be variable.

64. There are currently three-tiers to the complaints structure:

- to the NHS provider, with or without the support of an Independent Complaints Advocacy Service (ICAS);
- to the Healthcare Commission, following an unresolved complaint to the provider; and
- to the Health Service Ombudsman, following an unresolved complaint to the Healthcare Commission.

A complaint can also, depending on its nature, lead to litigation and be taken through the legal system.

65. ICAS aims to support patients and their carers wishing to pursue a complaint about their NHS care to agreed national quality standards. The Healthcare Commission becomes involved if a complaint is not resolved through the local NHS complaints procedure, and the Health Service Ombudsman reviews a complaint relating to the administrative processing of the complaint.

66. In addition a Patient Advice and Liaison Service (PALS) has been established in every NHS Trust and primary care trust (PCT). PALS are not part of the complaints procedure but might be able to resolve concerns informally and should be able to guide someone through the complaints procedure.

67. The Citizens Advice Bureau (CAB) was a contracted provider of ICAS in six of nine regional government areas in England. In 2005 it published a report *The pain of complaining* which looked at the NHS complaints procedure. It found that the roles of its constituent parts were lacking in supporting patients who faced:

- difficulties in finding out how to access the complaints system, because of a reluctance by Trusts to advertise the procedure and support services available through ICAS;
- lengthy delays at every stage of the process, as both Trusts and the Healthcare Commission fail to deal with complaints within their targets; and
- a culture which is defensive rather than responsive, failing to provide complainants with explanations of what went wrong, or apologies when mistakes have been made.

68. In particular the standard of the patient-facing entities, PALS and ICAS, were found to be variable. PALS are not run to any national standards, are often underresourced, and are used by services to capture complaints so they can be dealt with informally rather than alerting people to the formal complaints system. In regard to ICAS, where the complaints procedure works well it can be a force for making things better for individuals and the service. Where it works less well, it increases frustration and distress and the chance of the complaint being taken through the legal system.

69. *The pain of complaining* makes a number of recommendations amongst which it asks that the Department of Health set a national standards framework for complaints handling and that the Healthcare Commission ensures compliance with these standards through regulation. It also recommends that Trusts develop a mechanism to obtain feedback from patients who have used the complaints process and that, through OSCs, changes which should be made as the result of a complaint are implemented.

70. The Department of Health did not renew the CAB’s contract as the main provider of ICAS and so the complaints system in many areas of the country is currently unsupported. This is a very serious state of affairs.

71. The 2005 Health Service Ombudsman report into the NHS complaints procedure in England also identifies weaknesses in the complaints system, including:

- inflexible processes;
- timescales not centred on patient needs;
— a lack of capacity and competence of staff in dealing with complaints; and
— a lack of leadership, culture and governance. ²³

72. Often the complaints system fails at the first hurdle because patients simply do not know where to turn, in particular where a patient journey spans a number of providers. There should be a single portal for all complaints, the structures of which must be sufficiently resourced. Patients need to be properly advised and independently supported and should feel that it is safe to make a complaint and that it will in no way jeopardise their current or future care. Complaints procedures and structures are often complex and so there must be adequate investment to ensure that support staff are of high quality and sufficiently trained and equipped.

73. Principles of learning from mistakes and continual feedback should be central to all regulatory mechanisms. It is important that a single body at local level should be responsible for drawing together the monitoring work of complaints. There may be a danger that individual problems, while resolved for that individual, fall through the gap in terms of the bigger picture. Patients who complain are usually seeking an explanation of what happened, an apology if appropriate and reassurance that recurrences of the problem they encountered will be prevented. Complaints monitoring should also capture the failing of policy as well at that of care. The new Local Government and Public Involvement in Health Bill does not address patient complaints. ¹²

Q. In what circumstances should wider Public Consultation (including section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

74. The government uses national consultations to gather the views on policy and proposed legislation. Consultations are published on the relevant department website and sent to selected stakeholders. The general public can also respond individually, as can other interested organisations. Other forms of consultation have been addressed above.

75. The Cabinet Office has a code of practice for government consultations, setting-out criteria which should be met. ²⁴ These are:
— consult widely throughout the process, allowing a minimum of 12 weeks for written consultation at least once during the development of the policy;
— be clear about what the proposals are, who may be affected, what questions are being asked and the timescale for responses;
— ensure that the consultation is clear, concise and widely accessible;
— give feedback regarding the responses received and how the consultation process influenced the policy;
— monitor the department’s effectiveness at consultation, including through the use of a designated consultation co-ordinator; and
— ensure the consultation follows better regulation best practice, including carrying out a Regulatory Impact Assessment if appropriate.

76. There are a number of reasons why consultations are not being as effective in gaining stakeholder opinion as they could be, including:
— the sheer number;
— diverse initiatives—apparent lack of joined up thinking;
— length of documents;
— length of consultation time;
— scepticism that responses will be properly considered; and
— lack of public awareness of consultations.

77. The timeframes given to consultation are often unworkable, and even professional organisations like the BMA with the capacity and resources to respond have to work hard to do so. For individuals or for unsupported groups the deadlines give little scope for deep consideration and understanding, denying access to large swathes of the population. Time is one of the biggest barriers to gaining views from ordinary people or professionals.

78. Any attempt to use consultation as a tool for gaining public views should provide open and transparent information and not be used as “me trying to convince you that what I believe is true and should be done”.

Dr Vivienne Nathanson
British Medical Association
January 2007
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Evidence from Canterbury City Council Health Scrutiny Panel (PPI 113)

EXECUTIVE SUMMARY

1. Our submission reflects our concerns that the suggested move to LINks representing a geographic area based on the local authority with social services responsibility (in this case Kent County Council) will not be able to truly reflect the concerns of local people when it is covering a population of 1.4 million. It also responds to the issue of funding, and the power that will be invested in the LINk.
INTRODUCTION

2. Canterbury City Council is a district council in the east of Kent. The district has a population of approximately 140,000, split between the three main urban areas of Canterbury, Whitstable and Herne Bay, with a sizable rural population.

3. Although the City Council does not have statutory powers to scrutinise the NHS, our Councillors take a keen interest in health issues and see this area as fundamental to the well-being of the district. As such the Council has constituted a Health Scrutiny Panel which has been in existence for two years. The panel have been involved in joint working with the Kent County Council NHS Overview & Scrutiny Committee, and have close ties with the relevant PCT (Eastern & Coastal Kent PCT), and the associated PPIF.

EVIDENCE

4. We do not wish to respond to all the points contained in the terms of reference, just the specific terms of reference set out below:

5. **What is the purpose of patient and public involvement?**

6. We consider that patients and the public should be involved in designing and checking the services they receive. It is only when services are designed from the perspective of the end user that they can be truly fit for purpose. It is often only the end user that will be able to identify areas of weakness in the treatment they receive, this is why it is essential that the patient and publics are involved.

7. **What form of patient and public involvement is desirable, practical and offers good value for money?**

8. It is important that the practicality of patient and public involvement is kept at the fore when designing the new system of involvement. It is the practicality of the proposed LINk system that has concerned Canterbury City Council Health Scrutiny Panel.

9. Prior to the reconfiguration of Primary Care Trusts last year the people of Kent were served by nine PCTs and four Acute Hospital Trusts, each one with their own Patient and Public Involvement Forum (PPIF) to monitor and help improve the patient experience, and inspect services where relevant. In the case of the Canterbury district this meant that a PCT serving 165,000 people (Canterbury and Coastal PCT) had a PPIF representing the public voice, whilst another PPIF fulfilled the same role for the East Kent Acute Hospital Trust (which incorporates our district).

10. Moving to one body, co-terminous with the local authority with social services responsibility, means that this LINk will be tasked with providing a stronger local voice for 1.4 million people in Kent. We fear that a single body will struggle to represent the differing localities in a population of this size. There have been occasions in the recent past when decisions on relocation of services effectively placed the residents of East Kent in competition with those of West Kent. It could easily be seen that the concerns of both sets of residents would not be taken up as they would not be of “major importance to a whole population” (as detailed in Department of Health publication “Government Response to A Stronger Local Voice” p18: para 1.35).

11. It seems strange that a PCT and Acute Hospital Trust that each cover a population of 700,000 should not have a LINk of their own which they could turn to to ensure the involvement of the patient and publics. The panel would like to suggest that an alternative would be for each PCT to have an associated LINk, which is independent, and funded accordingly.

12. The bureaucratic structure that will need to be put in place to service a LINk serving 1.4 million people will be large, and will hamper the speed with which the LINk will be able to respond to issues as they arise. Also it will, by necessity need to have a central base, which will be difficult to access for large sections of the population. All these elements point to a body that will be dominated by well resourced organisations and their representatives, further reducing the input of ordinary members of the patient and publics.

13. It would seem that the aspirations of involving local groups as the eyes and ears of LINks will be hard to reconcile with the size of the area and populace that they are intended to serve. Practically it will be impossible to address the often competing concerns of the varying local groups. It will not often be the case that even groups concerned with similar conditions will have the same concerns in all parts of the county.

14. **Why are existing systems for patient and public involvement being reformed after only three years?**

15. The panel are concerned that there appears to be little justification for the reformation of a system that has been in existence for only three years, and which was just beginning to function effectively. A further
concern is the apparent lack of planning that has seen a reorganisation of PCTs without a simultaneous reorganisation of the patient and public involvement bodies, this has led to a situation whereby the existing PPIFs have had to reorganise themselves to match the new PCT structure, at a time when their future existence is limited. This lack of planning is further highlighted by the lack of clarity over the timescales. Originally the CPPIH was told that it and the PPIFs it supported would be abolished in June 2007, however it has now been told to continue its work until at least December 2007.

16. However, the panel is pleased that the new LINks will be urged to build on the work of the PPIFs, and encourage an element of continuance with PP1F members.

17. **How should LINks be designed, including:**

*Remit and level of independence*

18. The panel is pleased that the remit of the LINk will include social care as there are many areas of overlap between health and social care, and these are increasing all the time.

19. It is important that the LINk remains independent of both the Health Service and the local authority which is tasked with creating it. This is explained further in the response to the question of funding. Despite the need for independence, the panel felt that it would be important for the LINk to be able to draw upon the expertise of the NHS and local authorities.

*Funding and support*

20. The panel feels that it is imperative that the LINk is properly funded to do its job. As outlined above (para 12), the size of the county of Kent and its population size suggest that a large supporting structure will be necessary to ensure the LINk can even come close to being effective. Of concern then is the fact that the Department of Health in conjunction with the Department for Communities and Local Government have agreed that “resources to provide for support to LINks will be allocated as a targeted, but not ring-fenced, specific grant” (“Government Response to A Stronger Local Voice” p14, para 1.25).

21. This lack of ring-fencing in effect means that the local authority with social services responsibility will be able to decide exactly how much funding the LINk will receive. The two main concerns here would be that in a period of financial challenge in the local authority sector (Gershon responsibilities, Lyons review and CSR07) it is conceivable that the full grant will not be allocated to the LINk, but may be swallowed up by other priorities within the local authority. Also, it is again conceivable that if an effective LINk started to raise concerns over the social care aspects of their remit, then the local authority could reduce the funding to that LINk in order to reduce its ability.

*Statutory Powers*

22. The panel feels that it is imperative that the LINks retain the power of inspection that was afforded to the PPIFs, and that this role, whilst complimentary to the power of the regulatory bodies concerned with health, should be independent of such bodies.

23. **How should LINks relate to and avoid overlap with:**

*Local Authority structure including Overview and Scrutiny Committees*

The panel are keen that district authorities in a two-tier system are not isolated from the LINk system. It is often Councillors representing district wards who are the first point of contact for constituents with concerns. This role will be further enhanced by the Community Call for Action which is included in the Local Government Bill. At present it is unclear how the relationship between the LINk and the Community Call for Action will develop, and the panel would appreciate some clarity from the government on how district Councillors should be expected to work with LINks.

Canterbury City Council Health Scrutiny Panel

10 January 2007
Evidence submitted by The Centre for Public Scrutiny (PPI 62)

1. EXECUTIVE SUMMARY

1.1 People should have a range of ways to influence their well-being, health and care and outcomes from local activity should be shared locally, regionally and nationally in order to impact local, regional and national well-being, health and care policy.

1.2 Local councils should play a key role in ensuring that involvement frameworks are “fit for purpose” and are able to help “shape the place”. Frontline councillors (through overview and scrutiny or the Community Call for Action) should use their democratic mandate to ensure that decisions made by local councils, the NHS and other partners are influenced by local people.

1.3 The term “patient and public involvement” does not adequately capture the desired outcome of accountable well-being, health and care and should be changed to better reflect the need for people to be able to influence decision makers.

1.4 The ability for people to influence should be a strong “third pillar” of performance assessment in health and social care alongside safety and value for money.

1.5 SMART targets to measure a “joined up” approach in the public sector to well-being, health and care should be introduced into Local Area Agreements.

1.6 There is too little networking between non-executives (Councillors, NHS Non-Executive Directors and FT Public Governors). Such networks can help to promote a dialogue between communities, commissioners and providers about the balance between accountability and professional judgement.

1.7 An “institutional/organisational” structure is not best placed to deliver the range of opportunities that people need to be able to influence their well-being, health and care. A well resourced “community facing” structure that crosses organisational boundaries and reflects patient journeys will be better placed to deliver benefits for both patients and communities.

1.8 The distinct but complementary roles of all bodies seeking to influence well-being, health and care need to be understood, accessible and carefully co-ordinated to avoid duplication and to ensure that they work together for the benefit of local people.

1.9 The current 12 week “consultation window” is not an effective or efficient way to influence decisions and the public sector should work towards a system where patients, carers, communities and their representatives are able to influence change to the extent that “formal” consultation is not required.

2. INTRODUCTION

2.1 The Centre for Public Scrutiny promotes the value and potential of scrutiny in modern and effective government—to hold executives to account and to create a constructive dialogue between the public and its elected representatives—to improve the quality of public services. We believe that “better scrutiny means better government”. In the context of the Committee’s inquiry this principle should be applied to ensure that councillors as “community leaders” can be satisfied that local arrangements for patient and public involvement are able to facilitate reasonable, informed judgements between public opinion and professional judgement in ways that are understood and accessible to the public.

2.2 We promote four principles of good scrutiny that are mutually reinforcing and lead to improved public services through community leadership. These principles are outlined in further detail in “The Good Scrutiny Guide” (attached).

Good public scrutiny . . .

1. provides “critical friend” challenge to executive policy-makers and decision-makers;
2. enables the voice and concerns of the public;
3. is carried out by “independent minded governors” who lead and own the scrutiny role; and
4. drives improvement in public services.
2.3 Since June 2004, CfPS has been running a Department of Health sponsored support programme for health overview and scrutiny committees. The support programme will end in June 2007. As part of the support programme CfPS has published a guide for OSCs and Patient Forums about how to work effectively together (copy attached) and the Government response to *A Stronger Local Voice* indicates that CfPS will work with OSCs to develop relationships with LINks.

3. Purpose of Public and Patient Involvement

3.1 We believe that the purpose of patient and public involvement is to help decision makers reach decisions that demonstrably take account of the needs and aspirations of communities and individuals. In the context of well-being, health and social care, patients, carers and the public need to be involved at three levels:

- **Strategic**—improving health and well-being by prevention, treatment and care.
- **Local**—planning and delivering prevention, treatment and care services.
- **Individual**—decisions about lifestyle, treatment and care.

3.2 We believe that there is a distinction between “involvement” and “accountability” and that where involvement and accountability are operating effectively, the result will be “influence”. The term “patient and public influence” better expresses the desired outcome of demonstrable involvement and accountability. Furthermore, we believe the distinction between “patients and the public” is unhelpful and that a better expression should be found to capture the concept “can people influence?”. We believe that people should have several ways to influence, reflecting their multiple interests as patients, carers, citizens and representatives.

4. Desirable, Practical and Affordable Form of Public and Patient Involvement

4.1 The NHS Plan set out an aspiration to put people at the heart of everything that the NHS does. The ability for people to influence needs to be established alongside safety and value for money as three pillars of performance assessment across health and social care.

4.2 Organisational and system reforms have been put in place to help people get faster access to better quality treatment services but more work needs to be done across the public sector to better understand:

- how people live their lives;
- how to develop their capacity to experience a better quality of life; and
- how to help them when things “go wrong”.

4.3 People’s ability to influence their well-being, health and care needs to be a strong focus for:

- Commissioners in local government and the NHS.
- Providers in the public, independent and private sectors.
- Inspection Concordat partners.
- Monitor and Ombudsmen.

4.4 Commissioners need to show how they have incorporated people’s views in to decisions they have made. We welcome the indication that PCTs should do this through the Patient Prospectus, although more clarity is needed about how practice based commissioners will need to express their accountability to communities. GP practices should consult relevant ward councillors throughout the commissioning cycle.
4.5 The requirement to demonstrate accountability should be extended to well-being and social care, perhaps through council annual reports. We also welcome the indication that councils and PCTs should publish a response to Director of Public Health reports (an example of good practice can be found in Newcastle, where the health OSC provides a commentary on the DPH report).

4.6 Providers need to show how they have improved services (for example through patient/clinician dialogue, PALS and ICAS data). NHS Trusts need to explain why they cannot work with communities in similar ways to Foundation Trusts.

4.7 Inspectors, Monitor and Ombudsmen should show how their assessments and recommendations are informed and guided by people’s experiences. Monitor (and the Foundation Trust Network) particularly needs to identify how the Foundation Trust model has added value in the area of public influence over service design.

4.8 Local Area Agreements, building on the duty to co-operate in the Local Government and Public Involvement in Health Bill, should be strengthened by requiring SMART targets for public sector organisations to demonstrate a “joined up” approach to well-being, health and care.

4.9 We believe that someone has to balance professional judgement (the views of clinicians and managers about the best forms of service delivery) and accountability (people’s opinions and experiences). There should be a strong role for frontline councillors as community leaders to determine whether well-being, health and care have been and are being shaped around the needs and aspirations of patients and citizens. There is scope to create networks that bring together non-executives in order to make the most of their distinct but complementary roles. We are committing money from our OSC support programme in 2007 to support regional networks that can create opportunities for this to happen but this funding stream will not last beyond June 2007 and we believe that there is a gap to be filled into the future.

4.10 In terms of affordability we believe that each part of the framework needs to “do what only it can do” and that overview and scrutiny committees should be the guardian of the system locally, ensuring that it is “fit for purpose” in the local context. NHS bodies should be funded to provide opportunities for influence in proportion to their populations and there are opportunities for public bodies to co-operate, making use of existing engagement mechanisms developed by local councils for reaching their communities. These mechanisms may be strengthened through comprehensive community engagement strategies.

5. CURRENT REFORMS

5.1 A CIPS roundtable discussion on 30 November 2006 concluded that the current “anatomy of accountability” in health could be construed as a “crowded goldfish bowl” that lacks clarity about how the various parts can work together to achieve the best outcomes for patients, carers and citizens (transcript attached).

5.2 We believe that the current “institutional and organisational” structure for involvement (through 570+ Patient and Public Involvement Forums) is not best placed to deliver a range of opportunities for people to influence decisions about their well-being, health and care in ways that suit them. We believe that the best Patient Forums have delivered benefits for patients but it seems less clear whether overall they have added value for the public. We believe that the proposals for “community facing” Local Involvement Networks (LINks) will add value by providing opportunities for everyone to influence decision-makers in local government and health, across the patient journey regardless of organisational and administrative boundaries.

5.3 Given this community focus across health and social care, we believe it is right for councils providing social care to take the lead in procuring support arrangements for LINks. We will work with overview and scrutiny committees to help them hold council executives to account for the value they achieve from the targeted grant for establishing LINks, particularly in two tier areas where county councils will need to ensure that LINks are not remote from local communities.

6. DESIGN OF LINks

6.1 People’s opportunities to influence well-being, health and care will be “protected” through the legal requirement for commissioners and providers to reach out to communities when designing and running services (under the NHS Act 2006 and Part 11 of the Local Government and Public Involvement in Health Bill). This could be seen to be reactive influence, but good accountability also requires opportunities for proactive influence.

Proactive influence is currently expressed at a number of levels:

— Individual—patient/clinical dialogue, PALS, ICAS and Ombudsmen.
— Collective—patient forums, patient groups or advocacy bodies.
— Representative—scrutiny committees, public governors and non-executive directors.
6.2 These means to influence are valid but there is still a place in the framework for a mechanism to engage people who do not have single interests or the time to serve on formal bodies (including people whose views are generally not heard). We believe that the best LINks will make the most of their community focus to engage people in different ways. We believe that the proposed remit for LINks across health and social care is appropriate so that they can follow the “patient journey”. LINk visiting rights should extend right across primary and secondary care as the opportunity to gather information and experiences from patients in surgeries, clinics and wards is very important. These rights should also extend right across the public, independent and private sectors. We agree that these rights cannot reasonably be given to all LINk members but only to a few in each locality.

6.3 In terms of membership, it may be that LINks develop “constituencies” (for example people interested in particular services or types of provider) in a similar way to Foundation Trusts. Maintaining contact with a wide membership will be important for LINks but this could be expensive and there are lessons to learn from Foundation Trusts about how to manage membership participation. LINks must not become dominated by “factional interests” and local authorities can have a role in overseeing the genuine representativeness of LINks and guarding against undue influence of any particular group.

6.4 LINks will need significant resources and support, particularly if they are to maintain a membership base, conduct research and reach out in creative, innovative and inclusive ways. Support for LINks must go beyond simply administering meetings. Experience from our health scrutiny support programme shows that to be most effective, OSCs need specialist policy support and that direct funding stimulates new ways of working (see Sharing the Learning attached). We note that targeted funding will be given to social care councils to procure LINK hosts and this may provide opportunities to secure additional funding for LINks beyond central government grant.

6.5 Our experience from supporting scrutiny committees is that a tremendous amount of good work takes place that has an impact at local level (2,000 entries in our Review Library on our website at www.cfps.org.uk) but there is no mechanism for gathering “collective wisdom” in order to drive changes in national policy. CIPS is seeking to develop the capacity of its Practitioner Forum to perform this role in relation to health and social care. The point being that opportunities to share local work more widely is very valuable. This is distinct from national “co-ordination” that would not sit well with the flexibility that is suggested for the way LINks are established and run.

6.6 Since funding and performance management of LINks is to be directed through local government and the LINk role appears to sit within our definition of “public scrutiny”, there may be a role for CIPS to play (perhaps with partners such as the LGA) to provide mechanisms for sharing best practice through technology, events and publications building on our current model. In particular, our health scrutiny support programme provides a model of how best practice can be promoted through academic research, direct funding for action learning and expert advice and published guidance.

7. RELATIONSHIPS

7.1 As LINks will have a remit for social care that is different from Forums, they will need to understand how social care works and how it fits in to the overall picture of local government. Organisations such as CfPS, LGA and IDEa could provide awareness raising sessions for LINks and CIPS would be happy for our regional health scrutiny networks to involve LINks as appropriate.

7.2 LINks will have to develop close working relationships with overview and scrutiny committees. CIPS published a guide last year about how Patient and Public Involvement Forums and OSCs can work effectively together (attached) and we could provide similar guidance about LINk/OSC relationships. The key to effective and efficient working will be for LINks and OSCs to talk to each other about their programmes of work and to establish how to make the best of their distinct but complementary roles.

7.3 LINks should provide valuable intelligence for OSCs and OSCs should use outcomes from LINk activity to plan their own work and develop their recommendations. This will need careful co-ordination so that LINks and OSCs make the most of opportunities in the new framework. Given that there will be one LINk for each OSC area this co-ordination should be easier to achieve than the existing Forum structure.

8. PUBLIC CONSULTATION

8.1 CIPS is aware that the Commons Public Administration Committee has announced an inquiry about customer and user involvement in public services. In relation to health, it is vital that the NHS and local authorities engage people in decisions about well-being, health and care. Our guide about tackling substantial variations (attached) provides a range of practical examples of local agreements about what constitutes “substantial” in the local context. The LGiH Bill talks about “significant” changes to services and it should be a requirement for OSCs and the NHS to have a local agreement about local triggers for consultation. CIPS and the Independent Reconfiguration Panel could play a role to ensure there are common standards.
8.2 By tackling engagement together through local strategies, and by using LINks constructively, public sector bodies can demonstrate to their communities that there is “joined up thinking”, helping to restore trust in public services. Our recent roundtable suggested using patient lists could be a good basis for engaging patients for example. Local councils should ensure that Hosts make LINks aware of the range of opportunities to use local engagement activities to avoid “consultation fatigue”.

8.3 We believe that a positive step towards openness in decision making would be for the NHS to publish a forward plan of decisions (similar to a local authority executive forward plan of key decisions) to be made about service reconfigurations. This would enable some pre-decision scrutiny by OSCs and would provide a timetable for OSCs to form joint committees to respond to cross-boundary issues. The current 12 week “consultation window” is not an efficient or effective way to scrutinise major changes to health services. By involving local people, LINks and OSCs at an earlier stage it should be possible for the NHS to move to a position where formal “public consultation” in its current form is not required.

8.4 We would be happy to expand on our submission in oral evidence if the Committee would find that helpful.

Jessica Crowe
Executive Director
The Centre for Public Scrutiny
9 January 2007

Evidence submitted by the Cheshire and Wirral Partnership NHS Trust PPI Forum (PPI 33)

At our last meeting on 2 January 2007, the Patient and Public Involvement (PPI) Forum for the Cheshire and Wirral Partnership NHS Trust (CWPNT) authorised me to send you the attached three notes.

1. The note “Proposed Local Involvement Networks to replace PPI Forums” dated 9 August 2006 summarises comments on DH document 27857 “A Stronger Local Voice” dated July 2006 under the three headings:
   (a) what is good about the proposal;
   (b) what is not good about the proposal; and
   (c) suggested improvements.

2. The note “Feedback from Getting ready for LINks” dated 15 December 2006 summarises comments on DH document 7283 “Government response to A Stronger Local Voice” dated December 2006 and the “Getting ready for LINks” meeting in London on 13 December 2006 under the three headings:
   (a) clarification of powers of LINks;
   (b) next steps; and
   (c) concerns still to be addressed.

3. The note “A three layer model for Local Involvement Networks” dated 2 January summarises proposals for structure arrangements for LINks and foundation trusts under the three headings:
   (a) three layer structure arrangements;
   (b) governance checks and balances; and
   (c) specialist services crossing LINK boundaries.
   — “a LINk may well wish to set up specialist interest groups” (DH 7283 para 2.20) would be inconsistent and ineffective;
   — specialist LINks for specialist services would give rise to overlap and jurisdiction disputes; and
   — hence the proposal for “Specialist Joint Committees with full delegated powers for that specialist service”.

Murdo Kennedy
PPI Forum Chair
Cheshire and Wirral Partnership NHS Trust
8 January 2007

NOTE 1: PROPOSED LOCAL INVOLVEMENT NETWORKS (LINks) TO REPLACE PATIENT AND PUBLIC INVOLVEMENT (PPI) FORUMS

Final 6th Draft supported by the Mental Health PPI Forums NW Network and the West Cheshire PCT and Cheshire and Wirral Partnership NHS Trust PPI Forums
1. **What Is Good About the Proposal**

The proposal to replace PPI Forums with Local Involvement Networks (LINks) is set out in DoH document 275857 “A stronger local voice: A framework for creating a stronger local voice in the development of health and social care services” dated July 2006. Good points of the proposal are as follows:

(a) it will combine involvement in commissioning, providing, monitoring and regulating for social care as well as health care (ie “joined-up involvement in joined-up systems”);
(b) LINks will be linked to Local Authority Overview and Scrutiny Committees (OSCs) with strengthened powers to be consulted by commissioners, so decisions should be more locally accountable and transparent; and
(c) it will provide opportunities for broader membership, but LINk support must avoid repeating key mistakes made by CPPIH such as:
   - wasteful and confusing delay in producing the key Handbook;
   - over-emphasis on numbers rather than capability of members; and
   - over-emphasis on unfocussed central computer system (KMS).

2. **What Is Not Good About the Proposal**

Drawbacks to the proposal can be summarised as follows:

(a) lack of detail and guidance on models and governance for LINks, which will result in even greater delays and confusion than with the start-up of PPI Forums, hence exacerbating “post code lotteries”;
(b) over-reliance on OSCs with conflicts of interest which compromise their ability to act as an “independent watchdog”, since Local Authorities already both commission and provide social care and now they will also commission a host organisation to run their LINks; and
(c) LINks will have no power to require answers or entry, which will greatly impair their ability
   - to hold autocrats to account;
   - to penetrate cloaks of “commercial confidentiality”; and
   - to act as real “independent watchdogs”.

3. **Suggested Improvements (ie “LOGs for LINks”)**

In order to learn from previous mistakes, there is a need for:

(a) consistent national models and a governance handbook, with an ultimate right of appeal to a Regional Health Authority (following para 2b);
(b) a “LINk Overview Group” (LOG) of elected and trained volunteers for each LINk with powers to require answers and entry in order to able to act as a credible “independent watchdog”; and
(c) specialist (joint) LOGs for specialist trusts which cover large areas with multi-PCT (LA) funding, noting that many mental health trusts already have a three layer network with a high proportion of “expert” patients and carers in:
   - a “grass roots layer” of user and carer groups and open forums with users, carers and statutory and non-statutory organisations;
   - a “working layer” in working groups at all levels in the trust; and
   - an “overview layer” consisting of the independent PPI Forum.

**NOTE 2: FEEDBACK FROM “GETTING READY FOR LINks”**

(Comments from meeting in London on 13 December 2006)

1. **Clarification of Powers of LINks**

Progress since “A stronger local voice” (DH 275857, July 2006) is that the “Government response to a Stronger Local Voice” (DH 7283, December 2006) has addressed major concerns in that LINks will now have:

(a) powers to require answers within a specified timescale (paras 2.7, 2.25);
(b) powers of entry to health and social care premises (para 1.41), but restricted to LINk members who have received training to carry out visits in an appropriate and sensitive manner in line with a new “Visiting Code of Conduct” (para 1.42); and
(c) clearly defined independent funding for LINk support (paras 1.24, 1.25, 1.28).
2. Next Steps

Unlike the unrealistic across the board introduction of PPI Forums without a Guidance Handbook in January 2004, DH 7283 sets out three key preparatory steps prior to rolling out LINks:

(a) an “early adopter programme” (para 1.7) will pilot the development of LINks over a spectrum of seven areas in order to work up models, mechanisms and relationships (para 4.1) and protocols and guidance (para 1.9);

(b) a contract specification for host organisations is being developed (para 1.20) and “local authorities will be strongly encouraged to involve local people and organisations in the process of awarding the first contract to provide support to the LINk” (para 1.22); and

(c) stakeholders are encouraged to begin to plan how to prepare and develop new roles and relationships (paras 4.3 to 4.6).

3. Concerns Still to be Addressed

The DH Patient and Public Involvement Team are to be particularly commended for the extent to which they have listened and addressed key concerns, far less their preparations for the enabling legislation. However, three further concerns which need to be addressed are that:

(a) commissioners need to be discouraged from using “The primary function of LINks is to gather the views and experiences of people using health and social care services in their area” (para 3.6) as a cheap way of evading strengthened Section 11 responsibilities (paras 1.51, 2.9);

(b) quality starts with consistency, so in order to optimise the balance between flexibility and rigidity, the statement that “a LINk may well wish to set up specialist interest groups” (paras 2.20, 2.21) needs to be firmed up to “LINks have a duty to demonstrate effective collaboration for specialist services which cross LINk boundaries; and

(c) partly from 3b, it is necessary in practice for the LINk to have an appeal loop from the “Stewardship Board” (para 1.39) to an appropriate regulator (eg HCC, SCI).

NOTE 3: A THREE LAYER MODEL FOR LOCAL INVOLVEMENT NETWORKS (LINks)

(Authorised by the Cheshire and Wirral Partnership NHS Trust PPI Forum on 2 January 2007 for submission to the Health Select Committee Inquiry on PPI in the NHS)

1. Three Layer Structure Arrangements

It is useful to consider a simple three layer structure for a LINk and see how it would compare and interact with a parallel structure for a NHS foundation trust.

(a) The overview level

— For a LINk, this would be the LINk Stewardship Board (LSB) where the LINk would elect volunteers to the LSB to be trained and accredited to hold and exercise the powers of LINks to require answers and entry;

— these volunteers should bring specialist knowledge and experience;

— however, for the LSB to function in an effective and objective manner, they must agree to consensus non-partisan working.

For a foundation trust, this would be the Council of Governors.

(b) The working level

— For a LINk, this could consist of sub-groups led by LSB members to look into any part of the LINk’s whole system watchdog responsibilities (ie commissioning, providing, monitoring for both health and social care).

— For a foundation trust, this could consist of members selected by the trust for involvement in internal working groups and members selected by the Council of Governors for involvement in wider reviews including LINks.

(c) The “grass roots” level

— For a LINk, this would consist of the various service user, carer and voluntary groups covering speciality interests.

— For a foundation trust, this would consist of the foundation trust members in the various geographical or other constituencies.
2. **Governance Checks and Balances**

A simple approach here is to consider how checks and balances can be built in by allocating different roles to different organisations as follows:

(a) **LINK support organisation**
   - as well as administrative support, this would provide guidance in line with detailed national guidance in a handbook available prior to LINK start-up;

(b) **County Council**
   - this would maintain the register of organisations comprising the LINK, as well as providing a strengthened and tiered OSC network;

(c) **Health Care Commission/Social Care Inspectorate**
   - this could be seen to provide an independent appeal loop for the LINK LSB in the event of concerns or conflicts of interest with either 2a or 2b.

3. **Specialist Services Crossing LINK Boundaries**

For specialist services such as Mental Health, Oncology and Ambulance Services which are funded by more than one PCT and cover more than one LINK area, local flexibility has often resulted in “post code lotteries”. It is thus proposed that:

(a) LINKs should have a duty to demonstrate effective collaboration for specialist services which cross LINK boundaries;

(b) the most effective model to do this would be a Specialist Joint Committee to which adjacent LINK LSBs would have to delegate their powers for that specialist service; and

(c) the powers delegated to the Specialist Joint Committee would need to include the appeal loop to the Health Care Commission/Social Care Commission.

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**Evidence submitted by the Civil Service Pensioners’ Alliance (PPI 34)**

1. We are a campaigning organisation, which represents Civil Service pensioners. We are an independent, non-party political organisation with an elected Executive Council and an annual policy-making conference. We have about 65,000 members, who are retired from every Civil Service department, grade and location, and our income is derived from membership subscriptions. We receive no financial help from outside bodies. We are affiliated to many pensioner organisations, such as the National Pensioners’ Convention and Age Concern and, under their umbrella, we campaign on behalf of pensioners at large. We have about 100 local Groups throughout the UK who are in regular contact with pensioners. Therefore we are well placed to represent pensioners’ concerns. For the avoidance of doubt, we do not represent pensioners previously employed in the National Health Service.

2. We have previously welcomed the establishment of the Commission for Public and Patient Involvement in Health and also the Forums which have been established under its remit, involving interaction with Primary Care and Hospital Trusts at a local level. One of the strengths of the Forums has been their independence from the Statutory Bodies. They have also avoided the party political connotations, which exist within the local authorities. This independence has enabled them to initiate enquiries and surveys into the provision of services and, where appropriate, to seek changes from the position of authority which independence brings. A further beneficial feature of the existing Forums has been the political neutrality of the appointments and the wide age range of those appointed. We have welcomed the appointment of older people to the Forums, which has enabled them to understand the particular needs of older people who are dependent upon National Health Service provision.

3. Whilst we regret the demise of these existing bodies, we consider that the proposal to establish Local Involvement Networks can serve as an equally effective forum. We also welcome the proposal to include Social Care as well as Health issues. However, there should not be any reduction in the level of independence, nor should any age restrictions be placed upon appointments to the new bodies. It is important that the views and needs of older people should continue to be fully represented.

4. It is our view that the existing statutory powers should continue, with right of access to NHS premises to conduct inspections and investigations. These powers should be extended to enable inspections to take place in premises where the NHS contract services from voluntary organisations or commercial companies and to those providing residential social care. The re-organisation should be used as an opportunity to extend the provision of Public and Patient Involvement in the NHS and social care, rather than constrict it.
5. In short, the public should continue to have a say in what they require from the NHS and there should be provision to encourage the involvement of older people at every level and to consider their particular needs.

6. I hope that this submission is sufficiently clear but, should the Committee need any further explanation, we would, of course, be pleased to supply it either in writing or orally at a committee hearing.

John Amos  
Deputy General Secretary  
Civil Service Pensioners’ Alliance  
8 January 2007

Evidence submitted by the Commission for Patient and Public Involvement in Health (PPI 109)

EXEClUVE SMMARY

Patient and Public Involvement is essential for the achievement of key strategic objectives in health policy. A system of patient and public involvement should provide patients and the public with an effective voice alongside other decision makers in health and social care, locally, regionally and nationally. The PPI agenda has been characterised by uncertainty and indecision over the past four years and CPPIH has managed to progress the PPI agenda in difficult circumstances. Despite this considerable capacity for engagement has now been built, which should be nurtured under any new arrangements. The Commission welcomes the proposals to widen patient and public involvement. LINks as currently proposed are unlikely to deliver the objectives stated for PPI. Resourcing issues must also be examined to ensure that the aspirations laid down for LINks are attainable within the finances available to them, if the Government’s ambitions for LINks are to be delivered.

1. The Commission for Patient and Public Involvement in Health (CPPIH) was established by the NHS Reform and Healthcare Professions Act 2002 and became operational in December 2003. It is an independent, non-departmental public body, sponsored by the Department of Health.

2. CPPIH now oversees and supports 402 statutory Patient and Public Involvement (PPI) Forums, made up of local volunteers, one for each Primary Care Trust, NHS hospitals trust, mental health trust and ambulance trust in England. It also provides advice to the Secretary of State on patient and public involvement (PPI).

3. Since December 2003 there have been a variety of proposals and changes of direction affecting PPI Forums and the CPPIH. In June 2004, as part of the Arm’s Length Body Review, it was announced that the CPPIH would be abolished in 2006. This was subsequently postponed until summer 2007 and then to the end of 2007. This long period of uncertainty and unclear direction has significantly impacted on the development and achievements of PPI Forums and the CPPIH.

4. CPPIH welcomes the Health Select Committee’s inquiry and hope the Committee’s deliberations will contribute clarity and leadership in developing PPI policy. CPPIH is pleased to submit evidence for the Committee’s consideration and is willing to expand in oral evidence, if so invited.

THE PURPOSE OF PATIENT AND PUBLIC INVOLVEMENT

5. Public involvement aims at securing the accountability of decision-makers to the public, whether local or otherwise. The case for it derives from the right of citizens, whether or not they are current users of NHS services, to actively contribute to discussions about the use of public funds and the difficult and complex choices involved in applying finite resources to health and social care. Public involvement should be incorporated into decision-making on the development and planning of services including: service planning (what services should be provided), strategic planning (what should be achieved by delivering those services) and commissioning (who delivers services). It is particularly important to securing improved public or population health.

6. Patient involvement takes place at the interface between the patient and the actual operation and delivery of care. It aims to improve the effectiveness of services, and should contribute to securing equality in service delivery. Information gained from this process may also be used to inform higher level decisions about commissioning and operational delivery (how services are delivered and where).

7. Whilst there is a large amount of academic literature on patient and public involvement, there is a lack of agreement and clarity about what PPI is, what it is for and what national policy on PPI should be.

8. In CPPIH’s view, the objectives of PPI are to:

   — improve outcomes in health and social care;

   — facilitate citizens sense of “ownership” of health policy and services;
— secure equality of opportunity in receipt of health and social care; and
— address inequalities in the health of the population.

9. To further these objectives the role of a PPI system is to provide the public with an effective voice alongside health and social care professionals, service managers and planners, and national policy makers in all health related decisions-making.

10. In our view real progress has been made in recent years in joint decision making between individual patients and practitioners, and through initiatives such as the expert patient programme. However, there is still much to be done to deliver real patient and public involvement in decisions that affect health for groups, communities and indeed nationally.

11. There is evidence from many sectors (especially outside health) that involvement of stakeholders (especially those most affected by its outcomes) in decision making at all levels, including policy making, results in better decisions and ones which are understood and accepted by service recipients and taxpayers. However, this does require a change of culture within the NHS and social care and also amongst the public.

12. The role of PPI in securing longer term strategic objectives in health policy was underlined in the Wanless Report. It warned that failure to achieve a “fully engaged scenario” would have serious implications for the nation’s ability to resource health care in the future.

What form of patient and public involvement is desirable, practical and offers value for money?

13. The Kennedy Report, which emphasised the value of patient and public involvement (PPI) stated:
“The problem...concerns how, in a modern democracy, a public service such as the NHS can have embedded within it not only the principle that it exists to serve the public, but also mechanisms to ensure that this aspiration is translated into reality.”

14. Writing on deliberative democracy, the Stanford University academic James S Fishkin concluded that “getting the informed and representative views of the public requires a means to facilitate discussion and grant access to good information and differing experts, and a public space where people feel free to express themselves.”

15. Health professionals and health service managers have a well-established role in decision-making, as have institutional stakeholders such as local government in social care; historically neither patients nor the public have been included.

16. Fully involving patient and publics in decision-making requires the following to be in place:
— A clear policy direction.
— Supporting legislation, setting out rights, duties and governance.
— Appropriate resources.
— Sufficient capacity.
— A means of knowledge sharing.
— A process for escalation.

17. CPPIH believes there must be publicly funded mechanisms to facilitate patient and public involvement, not least because of the current pace of profound reform in health and social care. These mechanisms should be governed within overall legislative frameworks which provide:
— a remit to secure the full involvement of local communities;
— a statutory right for patients and the public to be involved in decision-making locally, regionally and nationally;
— a focus to address deficiencies in equality of access especially for those that are less often heard;
— a clear opportunity for escalation;
— processes to ensure value for money; and
— the ability to review and learn from experience in the rapidly changing environment of health and social care.

18. Involvement should occur at every level of decision making but should be appropriately focussed in order to be practical and provide value for money.

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10 ibid, “What is the Agenda for Public Involvement”.
19. In commissioning and planning a priority should be to secure a role for representatives of the public in decision-making and policy making locally, regionally and nationally. A useful model might be that of trade union representatives involved in collective bargaining, where a representative has the authority to negotiate with management on behalf of the work force derived from the fact that he or she represents the views and interests of other people.

20. This type of involvement would also be effective in improving public “ownership” of the challenge and complexity of decision making in health and social care involving finite resources in the service of ongoing and growing demand. There is strong evidence that understanding and commitment are much improved if people feel they have been actively involved, or properly represented, in decision-making.

21. Public involvement is key to addressing deficiencies in equality of access to health and care services by ensuring the needs of disadvantaged sections of the population, and of people with certain conditions, are properly met.

22. At a service improvement level, patient involvement should ensure that a wide range of experience is transmitted to and taken seriously by decision-makers particularly that of the less often heard. It should be a means to ensure that vocal and powerful patient interest groups do not dominate debate.

23. Patients can help secure efficient services, for instance by commenting on management processes that do not fit in with people’s needs. An example of this is the perverse practices used to achieve government’s target that all patients should be able to see a GP within 48 hours (itself the result of public demand) which in some instances, prevented patients from making advance appointments. Considerable inconvenience could have been avoided had the patient perspective been sought (and indeed GPs) and acted on at an earlier stage. As it was the issue was only taken seriously when it was raised with the Prime Minister on live television.

24. Patients can further contribute to effective service delivery by commenting on the human elements of treatment, for example on whether health professionals treat them with dignity and honesty, convey useful information about their treatment and make them feel confident they are getting the best care.

**Why are existing systems for patient and public involvement being reformed after only three years?**

25. Health and social care is undergoing substantial reform and it is to be expected that changes will be needed in the infrastructures for, and focus of, PPI especially as they themselves are still growing and developing.

There is therefore an ongoing need for formal review and assessment of how PPI is developing alongside this changing landscape of health and social care in order to provide evidence for any further changes to be made.

26. CPPIH agreed with the Department of Health’s decision to take a fresh look at patient and public involvement in the light of very significant NHS reform and changes in social care. We had already told the Department that the current arrangements are inflexible, including the statutory requirement of one forum per trust, and placed far too much responsibility on too few people to deliver effective public engagement, let alone on the scale required in the reformed NHS. The regulatory framework stemming from PPI Forums” inspection role brought with it a bureaucracy that many potential forum members found off-putting.

27. However, the reform process has unfolded against a background of constant change in policy and an unclear direction. Its origins lie in the Department of Health announcement in December 2003 that a review of Arm’s Length Bodies (ALBs) would take place in the first half of 2004, as it wanted to reduce the number of its sponsored ALBs, reduce the staff headcount and achieve a significant saving in expenditure. The Commission for Patient and Public Involvement in Health was included in the Review of ALBs only two weeks after it became operational.

28. At first it was expected that the DH would merge CPPIH with another ALB (probably the Healthcare Commission), however, on 22 July 2004 the Department announced it would be abolished.

29. On the day of the announcement of its abolition, the then Minister for Health, Melanie Johnson MP, said of the CPPIH:

“I emphasise that our decision to abolish the commission was not borne out of concerns about its performance. . . The commission’s performance, particularly its achievement in setting up the forums and recruiting about 5,000 members within a tight time scale, is highly commendable.”

30. It appears, therefore, that the ALB review was the initial driver of of PPI reform, rather than a change in PPI policy in Whitehall or concerns about CPPIH’s performance. Whereas CHCs had been in existence for about 28 years, CPPIH had hardly been operational for sufficient time to draw any conclusions about its effectiveness in carrying out its organisational and wider public responsibilities. However, the consequence of this decision was to leave the Department of Health with the task of finding an alternative body to oversee PPI Forums and appoint Forum Members.
31. At that stage PPI Forums were seen as continuing to play a vital role. The Health Minister Rt Hon Rosie Winterton MP had written to Forum Members on 28 May 2004:

“I want to reassure you that the future of PPI Forums is safe. PPI Forums whilst still in their early days are beginning to carry out valuable work and I am pleased with the progress that is being made. We do not want to waste the opportunity we have got with forums to make a difference to the NHS and people’s experience of it”.

32. This message was reinforced to Forum members in a letter from the CPPIH Chair and Chief Executive on 23 July 2004:

“Ministers have made clear that PPI Forums themselves will continue to exist, referring to them as the ‘cornerstone of the new arrangements’.”

33. It was also proposed on 22 July, 2004 that the NHS Appointments Commission would take over forum member recruitment and performance management and Forums would develop links with the Healthcare Commission. Meanwhile the numbers of Forums would be reduced, with the abolition of NHS Trust Forums, Ambulance Trust Forums and Mental Health Trust Forums. Instead, there would be one PPI Forum for each Primary Care Trust.

34. The Department of Health embarked on a limited consultation exercise which concluded in March 2005 that the remit of PPI Forums was too broad, and that forums should concentrate on monitoring and reviewing NHS delivery, seeking the views of the public and making recommendations to the NHS.

35. In August 2005, however, following a decision to postpone the abolition of CPPIH (scheduled for August 2006), to the summer of 2007, the Department of Health embarked on a Strategic Review of PPI and abandoned the proposals referred to in paragraph 33.

36. This coincided with other Department of Health policy streams: the national consultation exercise in autumn 2005 leading to the Our Health Our Care Our Say White Paper on healthcare outside hospitals and the publication in July 2005 of “Commissioning a Patient-Led NHS” which proposed to that Primary Care Trusts’ primary role would be commissioning, heralding a push towards a greater plurality of service providers, greater use of the private and voluntary sectors to provide services to NHS patients and the marketisation of the NHS.

37. CPPIH put forward proposals in November 2005 for supported local health networks, with a much larger individual membership, and local voluntary and community sector involvement, to the Minister of State for Health. We envisaged health networks being funded, supported, performance managed and championed by a new national body and developing from existing PPI Forums at their core.

38. CPPIH was inexplicably excluded from membership of the subsequent Expert Panel which sat between March and May 2006, chaired by Harry Cayton, Director of Patient Experience and Public Involvement at the Department of Health and Ed Mayo, Chief Executive of the National Consumer Council. However, we believe our proposals influenced the recommendations contained in “A Stronger Local Voice”.

39. CPPIH supports the department’s aim of introducing more local flexibility and ensuring more people are able to become involved.

LOCAL INVOLVEMENT NETWORKS

40. Decisions about health and social care are made at a variety of levels. While some are made locally in individual trusts, others are made in PCTs, local government, SHAs and nationally. To be effective, PPI and particularly public involvement needs to be in place at all of these levels.

41. In this context Local Involvement Networks (LINks) as set out in A Stronger Local Voice will achieve only some of the objectives set out in paragraph 4. LINks are likely to be most effective in delivering patient involvement in local decisions about operational delivery and providing patient and some public involvement in local commissioning decisions.

42. CPPIH has serious concerns about the LINk related clauses in the Local Government and Public Involvement Bill (clauses 153–164). Far too much is left to local discretion with little of the detail in the primary legislation, relying heavily on secondary legislation.

43. This is likely to result in a lack of uniformity and lead to significant service quality variations in LINKs (creating another postcode lottery in PPI). (Ironically, these were criticisms of the old Community Health Councils. (CHCs system, which led to the establishment of CPPIH.)

44. Moreover, being purely local organisations with a local remit LINKs as currently described will have no mechanism or remit for influencing for example regional decisions on major service redesign or reconfiguration, or on national policy.

45. The CPPIH view is that further attention should be given to national co-ordination and oversight as described in the following sections.
REMIT AND LEVEL OF INDEPENDENCE

46. Clause 153(2) of the Local Government and Public Involvement Bill sets out the remit of LINks. It states that the activities to be carried out are:

- promoting and supporting the involvement of people in the commissioning, provision and scrutiny of local care services (services provided as part of the health service in England; or services provided as part of the social services functions of a local authority);
- obtaining the views of people about their needs and experiences of local care and making those views known; and
- making reports and recommendations about how local care services might be improved to persons responsible for commissioning, providing, managing or scrutinising local care services.

47. CPPIH welcomes the inclusion of social services as well as health services within the remit of LINks. In addition we recommend that LINKs have additional responsibilities to:

- tackle the barriers to engagement, ensuring that powerful interests do not dominate debate or indeed their own proceedings; and
- address deficiencies in equality of access to services especially for those that are less often heard.

48. We are concerned that the legislation only refers to local care services. Additional mechanisms and approaches are required which can influence decisions at all levels including high level strategic and commissioning decisions. These mechanisms should involve LINks working together in a co-ordinated manner to provide involvement in these other decision-making processes.

49. Independence is important for the LINks to be credible and to avoid undue influence by health professionals, managers and local government, especially where local government itself is responsible for the provision of services. In the CPPIH experience the very fact that PPI Forums are independent organisations has been crucial to attracting volunteer members, yet the Bill is silent on this matter.

50. LINks should be accountable to local communities for the substance of their work, and to an outside authority, for performance management purposes—to ensure each LINk performs to national standards, offers effective leadership, works in line with best practice and has appropriate governance in place. To avoid conflicts of interest or politicisation the outside authority should not be an NHS body or the local authority. No such body is planned as a successor to CPPIH.

51. CPPIH regrets that the Local Government and Public Involvement Bill makes no provision to hold individual LINks to account beyond the requirement to produce an annual report according to the direction of the Secretary of State.

GOVERNANCE

52. To ensure the LINk performs effectively, it should, by statute, have a governing body on which representatives of individual members and representatives of the local community may serve. This body would be responsible for making decisions about its work and the allocation of resources, communicating with the wider membership and representing the LINk to stakeholders, the media, elected representatives etc.

53. The governing body should be required to adhere to Independent Commission on Good Governance in Public Services standards to ensure the LINk is well directed and controlled, and has transparent rules for making decisions about objectives, priorities and its use of public money.

MEMBERSHIP AND APPOINTMENTS

54. CPPIH regrets that the Local Government and Public Involvement Bill is silent on membership and governance of LINks and does not allow the Secretary of State the power to make regulations on such matters. We believe the LINk should have a formal membership and actively encourage and support new members and recommends the Bill be amended accordingly.

55. The CPPIH welcomes and strongly supports the move towards broadening and simplifying LINK membership. However, we continue to urge an evolutionary transition from PPI Forums to LINks. In the past three years, forum members have acquired considerable knowledge of their local NHS, and developed relationships with trusts, with local community organisations, with the public and with Overview and Scrutiny Committees. That experience and those relationships will be crucial to making the new system work.

56. For individuals, membership would confer benefits such as access to training, a right to submit proposals for the LINks work programme, and the right to take part in LINks internal decision-making. Members would also receive information and access opportunities for wider involvement in civic life.

57. Voluntary and Community sector organisations should also play a significant part in the LINks work. There could be a federal membership structure with separate sections for individual members and representatives of VCSOs.
58. There should be some national criteria and rules for membership to avoid the inconsistency in membership rules (and indeed governance arrangements) which were a feature of Community Health Councils and which the Department of Health itself used as a justification to abolish them.

FUNDING AND SUPPORT

59. The CPPIH experience of the the current Forum Support Organisation system demonstrates that support needs to be available locally, based on providing secretarial, administrative and organisational support, research and outreach.

60. Capacity for effective involvement is currently limited and needs to be nurtured, to encourage and promote involvement and ensure that people have the level of knowledge and understanding of how health and care services are organised and delivered and of the decision-making processes to contribute effectively.

61. Effective PPI requires a substantial investment in capacity building, particularly within local authorities serving large or diverse populations, or large geographical areas with both urban and rural communities, or areas with high levels of deprivation.

62. To achieve this, training and support needs to be available to participants, particularly those who have not engaged with healthcare decision-makers before.

63. CPPIH (and other organisations) have begun to build capacity for involvement in service improvement and operational delivery, although this is a continuous process and needs to be sustained. We have begun capacity building in the areas of PPI in commissioning but this is still at an early stage. Capacity for PPI in the development and planning of services still needs to be developed.

64. LINks should also have access to research, policy and communications capacity to match that available to commissioners and providers of health services.

65. Policy and strategic decisions affecting local healthcare are also made regionally by SHAs or by national government, therefore local PPI organisations will benefit from a means to share information and good practice, comment on health and social care policies, work together in a co-ordinated way and have an effective escalation process to ensure involvement in regional and national decision making.

66. There should also be a national framework of support to carry out detailed research, procure legal and policy advice, share best practice and facilitate communication between LINks.

RESOURCES

67. The Government response to a Stronger Local Voice set out a huge range of tasks for LINks including developing relationships with a wide range of individuals and organisations and maintaining regular communication in a wide variety of formats, collecting information from a wide range of sources and passing that on to commissioners and providers of services, regulators and inspectorates; developing specific relationships with local commissioners, service providers, OSCs and regulators of health and social care; acting as a hub for networks of service user groups and other organisations.

68. A considerable budget will be required to realise the Government’s ambition of the public being involved in decision-making, particularly involvement with commissioning and the development and planning of services. CPPIH recommends that decisions about proposals to reform PPI are made in full knowledge of the resources and funding that will be made available to deliver them.

69. The legislation that established PPI Forums and the CPPIH was decided in the absence of this information and consequently many of the intentions of that legislation were unachievable due to funding restrictions.

70. Historically, very limited resources have been devoted to PPI. In 2005–06 the Department of Health expenditure was £74.8 billion; the CPPIH budget was £31.7 million, (reduced to £28 Million in 2006–07). CPPIH and PPI Forum expenditure thus represented 0.04% of the total Department of Health spend in 2005–06.

71. An analysis by the Commission on the budget required to deliver even the local LINk proposals gives a budget requirement of £64 million—more than twice the CPPIH budget. It should be remembered that many LINks will be required to deliver PPI over large geographical areas.

72. In 2006–07 CPPIH had a budget of £28 million and if all of this money was divided equally between the 150 LINks this would amount to circa 180k each. Our understanding is that a formula will be applied so LINks that cover a bigger population ie Manchester will receive more than LINks that cover a much smaller area ie Isles of Scilly. Based on our experience of running Forum Support Organisations a typical LINK would need to receive a budget of over £424k. CPPIH can provide a breakdown on request.
Areas of Focus

73. LINks should focus on securing systematic local public involvement in improving health, social care and public health, from local service improvement through to commissioning and strategic decision-making. This is not just about gathering and presenting public views but helping people input directly to decision-makers and securing change based on that input.

74. They should also work together in a co-ordinated way and have an effective escalation and representation process to ensure involvement in regional and national decision-making.

Statutory Powers

75. These are important to ensure LINks avoid becoming mere talking shops and are able to make a real impact on decision-making.

76. CPPIH is pleased that the Local Government and Public Involvement Bill confers on the LINk the right to demand (and receive) information from service providers and make reports and recommendations. However, we are concerned that rights of referral to Overview and Scrutiny Committees seem to be restricted to referrals of social care matters.

77. PPI Forums have powers under the NHS Act 2006, to refer any matter they consider appropriate, for consideration by a relevant overview and scrutiny committee, or any other authority the Forum thinks fit.

78. Clause 156 of the Bill (Service Providers duties to allow entry to authorised representatives of the LINk) includes provision for conditions to be satisfied before a duty arises, including:
   — provision limiting the extent of a duty;
   — provision for imposition of conditions and restrictions;
   — limitation of the duty to allow entry to certain types of authorised representative; and
   — limiting the hours during which a duty applies.

79. Existing Forum members have been clear about the value they perceive in their existing powers of inspection. While the CPPIH welcomes the inclusion of these powers it fully supports the limiting of them to a restricted number of authorised representatives of each LINk. In our view this supports the need for some powers of inspection but also supports the objectives of wider involvement and simplification of the general membership processes.

We are, however, concerned that the proposed rights of entry are more limited than those currently enjoyed by PPI Forums and urges conditions to be kept to a minimum.

80. Representative of LINks with powers to enter premises where services are provided, will have to be subject to inquiries into their suitability, including criminal records checks as PPI Forum members currently are. The government must make clear who is responsible for these inquiries and for training authorised representatives in the effective use of powers and how these activities will be funded and resourced.

81. CPPIH recommends that LINks should also:
   — Have powers to commission research and other work from outside organisations when necessary.
   — Have the means to develop guidance and share best practice as well as to raise public concerns at regional and national level. It would be more cost effective to provide such support at a national level.

82. CPPIH recommends that there should also be statutory rights for the public to participate in decisions about strategic commissioning and service planning and the power to secure a review of decisions if it believes they were taken without meaningful consultation or effective patient and public involvement. These strategic decisions may often be made at regional or national levels and mechanisms must be provided for LINks to work together to provide involvement outside their local remit.

Relations with Local NHS Trusts

83. CPPIH agrees LINks should focus on the “whole patient’s journey” rather than on institutions. Nevertheless, they will need effective relationships with trusts, which should draw on their ability to network. LINks should play the role of the trust’s critical friend, making available advice and local knowledge. A relationship with the local LINk would be one of the means by which Trusts could involve people. However, merely involving the LINk would not relieve the trust of its duty of wider consultation.

84. The current experience of PPI Forums associated with specialist Trusts has clearly demonstrated the value of these specific relationships. With the planned abolition of PPI Forums, mechanisms need to be in place to ensure that this value can continue to be delivered within the larger LINks. There is a need to ensure that specific relationships with specialist Trusts can be maintained for service users.
National Co-ordination and Oversight

85. Given time, local LINks may themselves develop mechanisms for working together and gaining involvement in regional and national decision-making provided that those opportunities are made available to them.

86. However, the experience of the CPPIH is that, in the same way in which capacity has needed to be built at a local level for local involvement, some driving and supporting mechanism is required to build capacity for regional and national involvement. This is especially so in strategic decision-making, planning and development of services if these are to occur in the timeframe required to support the significant changes and reform currently underway in health and social care.

87. Throughout this section we have identified the need for a framework outside the individual LINks to:

— Support patient and public involvement at regional and national levels.
— Provide co-ordination for local LINks to work together.
— Encourage communication between LINks and the sharing of best practice.
— Provide leadership for capacity building.

88. And a national framework for service quality and governance to ensure a degree of consistency in LINks local operations.

89. There is therefore an ongoing need to review and assess how PPI is developing alongside the changing landscape of health and social care.

90. This framework should have access to the knowledge and expertise built up by CPPIH and could evolve from the existing organisation. An appropriate body to deliver these functions should itself be independent of government and accountable to Parliament.

91. Based on the CPPIH experience with PPI Forums and NHS trusts there is bound to be disagreement from time to time between independent PPI organisations and health and social care managers and professionals, and seek to ensure that public concerns can be built onto the policy making process at local regional and national level. A national organisation would, for example, help a LINk raise issues which cannot be resolved locally or which have regional significance, with strategic health authorities. In cases where there is a national dimension, it could provide a powerful voice for LINks at national level.

How Should LINks Relate To and Avoid Overlap with Other Bodies

92. There are many mechanisms for involvement, of which LINks will only be one. All public sector organisations should seek to involve the public in their work and it is inevitable the work of LINks will overlap with this. Given the current stage of development of PPI it is unavoidable that there will be multiple mechanisms, multiple opportunities for the public to be involved and some confusion and overlap. However it is important that LINks remain a clear independent voice to provide involvement even where other mechanisms are not in place or are not fully effective. However, more will be achieved through co-operation and LINks should be encouraged to develop productive relationships with other bodies.

93. The current structures for health and social care planning and delivery are only now beginning to move towards a “Patient led NHS”. In addition to professional dominance within health and social care, there is a democratic deficit as neither the public nor their representatives can force local decision-makers in PCTs and trusts to reconsider proposals. One of the aims of PPI should be to help promote democracy and accountability, and this should be embedded in the relationships of LINks with other bodies.

Overview and Scrutiny Committees

94. A report published by the Centre for Public Scrutiny found that the Overview and Scrutiny Committee “holding to account” function is underdeveloped.12 OSCs have no powers to overturn decisions, relying instead on persuasion and argument for influence. Productive relationships with LINks should help OSCs develop that role, with LINks acting as expert witnesses. They should be able to refer inform and advise the OSC, have the right to have their issues placed on the OSC agenda and have speaking rights.

95. LINks and OSCs should be encouraged to carry out joint planning of work programmes, but without compulsion on LINks to adopt the OSC’s priorities.

96. Overview and Scrutiny Committees may refer matters to the Secretary of State for Health, but it is she, not the OSC, who makes the final decision. PCT and NHS Trust Boards are accountable to the Secretary of State, not to representatives of local communities.

**Foundation Trusts**

97. As with all Trusts, LINks should play the role of the trust’s critical friend, making available advice and local knowledge. A relationship with the local LINk would be one of the means by Trusts could involve people. However, merely involving the LINk would not relieve the trust of its duty of wider consultation.

98. The primary roles of Foundation Trust boards and members councils are related to governance of institutions. They are not representative in nature, they do not guarantee accountability through patient and public involvement and the two roles should not be confused. The first responsibility of board members is to the board, not to the community.

99. Foundation Trusts are not accountable to the Secretary of State, instead local residents registered as members of the foundation trust have the right to vote for members of the board of governors. It is unclear how foundation trust members can exercise real influence over the running and development of the trust. Moreover, membership of foundations trusts is self-selecting and not representative of many groups within local communities.

100. LINks should, however, be encouraged to develop relationships with Foundation Trust Boards and members councils without compromising their independence.

**Inspectorates**

101. LINks will need to work closely with inspectorates, such as the Healthcare Commission and Commission for Social Care Inspection, to be an active stakeholder in annual performance reviews by Trusts and by regulators and in between those to alert them to serious concerns about service providers. CPPIH recommends LINks be given the power to refer matters of concern to an inspectorate as appropriate and that the Inspectorates have a duty to consult LINks.

102. It is vital that inspectorates also involve the public in decisions about their own activities. PPI has a key role to play in public accountability of the role of inspectorates themselves.

**Complaints Systems**

103. CPPIH does not envisage LINks playing a role in assisting or acting as advocates for individual complainants. However, information about services generating significant numbers of complaints would alert LINks to service issues in their local area and should be regularly provided in summary form.

104. In addition LINks should have a role in establishing patient and public views on the performance of the Independent Complaints Advocacy Services.

**Public Consultation over Changes to Services in Both Primary and Acute Sectors (Section 11 of the Health and Social Care Act 2001)**

105. The value of consultation is that it brings the public together in making decisions about finite public resources. This should happens at all levels locally, from service delivery to commissioning and strategic planning, and nationally at the policy level. CPPIH welcomes the Committee’s attention to Section 11 of the Health and Social Care Act, (now section 242 of the National Health Service Act 2006).

106. There should be an explicit duty on health and social care decisions-makers to consult LINks. At a minimum consultation should be carried out on decisions about the following:

- What services should be provided.
- Reconfiguration of services.
- Where services should be provided.
- The criteria for outsourcing services.

107. We are concerned that the proposed amendments in clause 163 of in the Local Government and Public Involvement Bill narrow the range of issues on which consultation is required to proposals which would have a substantial impact on the manner in which the services are delivered to users of those services, or the range of health services available to those users only.

108. The Committee will recall there was no requirement to consult under section 11 over the recent PCT reconfigurations as these were classed as managerial and administrative decisions by the Department of Health and considered to have no connection to service delivery. The consequence of this was that objections that such changes could adversely impact on service delivery were overridden.

109. CPPIH recommends that there should be a requirement to consult on major structural change such as large scale reconfigurations of organisations charged with securing the delivery of public services.

110. Similarly in the case of Pam Smith v North East Derbyshire PCT, established the principle that the public should be consulted on the outsourcing of local NHS health services.

111. CPPIH recommends PCTs have a duty to consult on outsourcing of NHS health services and build local concerns and wishes into tendering processes for commissioning services.
112. Finally, there is a widespread public perception that consultation occurs after decisions have already been made, and that taking part will not materially affect the outcome. CPPIH welcomes the new duty in clause 164 of the Bill for PCTs to report on consultation arrangements and the influence that the results have had on commissioning decisions. (Clause 164).

113. CPPIH recommends Clause 164 include a duty on PCTs to ensure that decisions on options for consultation are open to public influence and clearly reflect local wishes and concerns. This could be modelled on the Disability Equality Duty under the Disability Discrimination Act 2005 which creates a duty on public authorities to involve disabled people in developing their disability equality schemes.\(^\text{13}\)

Commission for Patient and Public Involvement in Health

10 January 2007

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Evidence submitted by the Commission for Social Care Inspection (PPI 144)

1. INTRODUCTION

1.1 The Commission for Social Care Inspection (CSCI) is the single social care regulator for England. The Commission is a statutory body whose primary function is to promote improvements in social care—across children’s and adult’s services, in local councils, and in the private and voluntary sectors of social care.

1.2 CSCI welcomes the opportunity to submit evidence to the Health Committee on the subject of patient and public involvement in the NHS. CSCI is the body set up to register, inspect and report on social care in England. Our job is to improve social care and to stamp out bad practice. We assess social services functions in 150 local councils and our inspectors visit over 26,000 registered services.

2. WHY WE ARE SUBMITTING EVIDENCE

2.1 CSCI has a strong commitment to involving people who use care services in our work and to ensuring that the bodies we inspect involve their service users as widely as possible. We were represented on the Expert Panel on the future direction of PPI. The panel’s work formed the basis of *A Stronger Local Voice*, which sets out proposals for LINks. Some of our evidence draws on information considered by the panel. In particular we endorse the panel’s advocacy of a commitment to develop and build public involvement in more flexible and creative ways, rather than taking an over-prescriptive approach.

2.2 In line with the policy set out in the White Paper, *Our health our care our say*, the recommendations in *A Stronger Local Voice* apply to social care as well as to health services. So at CSCI we think it is vital that plans for LINks take full account of the particular context of social care. We believe that you cannot make recommendations on patient and public involvement in the NHS without understanding how involvement works, and needs to work, in social care. Our comments are mainly related to adult social care, as most of CSCI’s responsibility for services for children will be moving to the new Ofsted before LINks come into being. However, as LINks will be concerned with services for people of all ages, we have referred to our experience of working with young people where we think it is relevant.

3. THE SOCIAL CARE CONTEXT

3.1 There are some obvious links between health and social care, not least the overlap in the population of regular users (older people, disabled people). However, there are significant differences:

<table>
<thead>
<tr>
<th>Social Care</th>
<th>Health Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rationed (based on “eligible” need)</td>
<td>Universal (based on clinical need)</td>
</tr>
<tr>
<td>Means tested</td>
<td>Free at point of use</td>
</tr>
<tr>
<td>Social model (changing the environment around the person)</td>
<td>Curative/Rehabilitative (changing the person)</td>
</tr>
<tr>
<td>Mainly long term</td>
<td>Mainly short term</td>
</tr>
<tr>
<td>Cash available in lieu of services (direct payments)</td>
<td>Cash in lieu of services not allowed</td>
</tr>
<tr>
<td>Main adult user groups relate to disability and age</td>
<td>Main user groups include those relating to disability and age but also many others eg maternity, accident and emergency</td>
</tr>
</tbody>
</table>

\(^{13}\) Disability Discrimination Act 2005 Section 49a. See also Guidance for public authorities on how to effectively involve local people Disability Rights Commission July 2006.
Current thinking in social care is driven by the social model of disability. This is about enabling people to be active players in society, fulfilling their potential by removing the barriers that might prevent this.

3.2 Within social care there are many good examples of user-designed, user-managed services, which can provide a model for devolving power to users. There is also more experience of user designed and user managed research than is the case in health care, and some creative examples of involvement for children and young people.

3.3 Current initiatives are giving individuals the capacity to purchase their own care and design their own structures of support outside the health and social care professions, a different but significant form of “involvement”.

3.4 Most people want involvement at a local or even personal level. In the new landscape of “personalised” services, user involvement needs to include user control of the services closest to them. It is important that LINks take account of these developments.

4. Using existing knowledge and good practice

4.1 There is significant body of research on user involvement in social care (for both adults and children), which has been collated and evaluated by the Social Care Institute for Excellence.ii

4.2 One of their overall findings was that people who are social care users are often marginalised in more general community involvement work (for example people with learning difficulties or very frail older people are often left out of general consultations and deliberative events). But good, tested models for their involvement exist.

4.3 One of the repeated findings of research is how certain groups remain marginalised in wider involvement activity. There is a need to pay particular attention to people with minority communication requirements such as BSL or people with non-standard communication requirements, such as people with multiple impairments who do not communicate in words. “Not everyone is equipped to speak up. Everyone wants to know their views are taken into account” as one user told CSCI recently.iii

4.4 LINks need to be inclusive in their working methods, and to use of good practice from previous involvement activity in both health and social care. They need to be set up and to operate in ways that empower people who use services.

5. Focus

5.1 A major focus of the work of the LINks will be on commissioning. The Overview and Scrutiny Committee (OSC) will need to work with the LINk to assess the quality of local commissioning. Ideally, work on service change and improvement will be collaborative; the involvement of people who use services will start from the belief that they have as much expertise to contribute as any other participant in the process.

5.2 The best person to comment on whether a service is good is the person using it. This is especially true for people with long-term conditions, and this includes most people who use social care services. This basic premise should be upheld when designing any system where people might make judgements on behalf of the people who are using the service.

5.3 The person who uses the service needs to be involved, and needs to be supported in ways that let them demonstrate their expertise. In practical terms this means things like providing planning information in accessible ways. In process terms it means involving people who use services at a sufficiently early stage that their input can make a real difference, including whole-scale redesign if required. It means developing specific opportunities for involvement for young people. There needs to be a developmental model, enabling individuals to gain as well as share knowledge, and enabling organisations to be sustainable. User-led organisations need a lot of support and investment to enable them to play an equal role in partnerships with commissioners and providers.

5.4 LINks have a vital role to play in making sure that this support and investment takes place. LINks should provide a flexible vehicle for communities and groups to engage with health and social care organisations, will support and promote voluntary and community organisations locally and will promote public accountability in health and social care through open and transparent communication with commissioners and providers.

6. Statutory powers

6.1 CSCI welcomes the proposals in the Local Government and Public Information in Health Bill to give service providers a duty to respond to requests for information, reports and recommendations from LINks. (clause 155)

6.2 We also welcome the power set out in the Bill to give LINks powers to refer social care matters to OSCs and the duty on the OSC to respond. (clause 157)
6.3 CSCI is concerned at the proposals set out in the Bill to give LINks rights of entry to premises, notwithstanding the conditions that will accompany this right. Clause 156 allows the Secretary of State to make regulations imposing a duty on service providers to allow authorised representatives to enter and view, and observe the carrying-on of activities on, premises owned or controlled by the services-provider. We feel that this proposal does not take account of the difference between a health setting such as a hospital or clinic and a social care setting such as a care home.

— Care homes are just that—the homes of the people who live in them. Many are small, catering to only three or four people.
— Although the proposals are for representatives to observe activities not to inspect them, we feel that in practice this difference will not be clear to the provider.
— We believe that it is important that people living in care homes have as much say as possible about who comes into their home. We can see a value in residents inviting a representative of the local LINk to visit.
— But we remain concerned that LINk representatives would view their role as quasi-inspection and that it would be experienced as quasi-inspection. We think that the proposal runs counter to the current drive to reduce the volume of inspection experienced by providers.

6.4 CSCI recognises the benefits of having non-professional input to the inspection process. We have worked extensively with people who use social care (including younger people) to find out what type of inspection they want. We have developed various methods to gather the views of individual care users, through surveys, one to one discussion and other direct communication. In addition, we employ “experts by experience”, people who use social care services who join the inspectors on site visits to give a view of the service. All these methods have been piloted and evaluated, and people who use services have been integrally involved in their design and in their implementation. For example, our picture based communication kit was developed by Bristol and South Gloucester People First, a self-advocacy organisation of people with learning difficulties.

6.5 Although CSCI’s existing work on experts by experience was recognised by the Government in their response to the consultation on A Stronger Local Voice, we do not feel that the relationship between existing inspection work and the proposed visits by LINks have been sufficiently thought through. There is nothing in the current Bill that guarantees that visits to premises will be focused on giving people who use services a direct voice; instead they read as if they will reproduce older models of public involvement, where people speak on behalf of those who use services.

7. LINks Relationship with Inspectorsates, Including CSCI and the (to be Established) Social and Healthcare Commission

7.1 We welcome the setting up of LINks as a co-ordinator of local involvement. We endorse the view that LINks should have the right to be involved and to be consulted by NHS and social care organisations. Equally, they should expect transparent and public communication with NHS and social care organisations. This includes the regulator, and CSCI will be committed to building working relationships with LINks, including receiving information about services from them. We see LINks as an important co-ordinator of local knowledge about service quality and an important conduit for the voices of people who use services locally. We welcome their role in bringing issues about social care to our attention and hope we will be able to work with them in gathering and checking evidence about services locally.

8. Formal and Informal Complaints Procedures

8.1 It is already open to any member of the public to refer a concern about a social care service to CSCI. We expect that LINks will have a role in facilitating this sort of referral. We would also expect that their position as co-ordinators of involvement across an entire area would enable them to identify patterns of complaint and to draw relevant bodies’ attention to these.

Dan Murphy
Commission for Social Care Inspection
January 2007

References
i The Joseph Rowntree Foundation has supported a wide range of user-managed research, see www.jrf.org.uk
ii Has service user participation made a difference to social care services Sarah Carr SCIE 2004.
iii Real Voices, Real Choices, CSCI, 2006.
Evidence submitted by Contact a Family (PPI 8)

1. SUMMARY

1.1 It is impossible for one small group of individuals to be able to represent all the different groups of service users. In our view local LINk groups could facilitate a process whereby commissioners and providers are made aware of patients’ experiences of local health services, appropriate action agreed and resulting outcomes fed back to the local community.

1.2 Voluntary organisations and community groups are often aware of the difficulties their members have in accessing services and can assist in facilitating this. Individuals from these organisations could be co-opted onto the LINk to work on specific projects.

1.3 Commissioners, members of LINk and local community groups need to know how to make participation work effectively. If patient/carer participation is carried out poorly and not seen as being effective, people will not wish to get involved. By contrast where patient participation is seen to work well and influence the way services are delivered people will be motivated to continue to be involved.

2. CONTACT A FAMILY

2.1 Contact a Family is the only UK wide voluntary organisation supporting all families of disabled children, regardless of the child’s medical condition. As an organisation we are committed to empowering parents and helping them to become involved in shaping the services that their disabled children need. We recognise that in order to develop better health services it is necessary to get feedback from people receiving services as to what their needs are and how well they are being met.

2.2 Contact a Family has a great deal of experience of consulting with families of disabled children and have developed various information resources on the topic including a Parent Participation: professionals’ guide, which covers the key principles involved in successful participation. (Parent Participation—improving services for disabled children: Professionals’ guide (2004) published by Contact a Family and Council for Disabled children).

2.3 Contact a Family is currently engaged in a three year project with the Royal College of Paediatrics and Child Health—“The Parents and Paediatricians Together Project”. The project’s essential concept is to create effective partnerships between the parents of disabled children across the UK and the paediatricians and other paediatric health care staff who work with them. The project has two main aims—to ensure that every parent across the UK whose child is born or diagnosed with a disability or rare disorder is automatically put in touch, through their paediatrician, with Contact a Family and to open up new opportunities for parents of disabled children to influence paediatric and child health services across the UK, by creating new frameworks for cooperation between parents and paediatricians. The author of this submission, Sheila Davies, is currently the England lead for this project.

3. KEY ELEMENTS TO PARTICIPATION

3.1 To understand how services are delivered and identify shortfalls in services it is necessary to seek feedback from a range of patients, including different groups of service users such as older people, children and adolescents who all have their own specific needs. They can receive services for both acute and long term conditions in a variety of settings, including the home, GP, community centres and hospital. There are particular obstacles for certain groups such as disabled people, asylum seekers, and looked after children and extra resources may be needed to hear their views. Parents of children with long term medical conditions, including those with complex health needs, are another such group. Their children often receive care from more than one health professional, who can be working in different settings and their care can requires coordination across different agencies. However parents of children with long term disabling medical conditions are least likely to have time to get involved with ongoing participation as much of their time is taken up in caring for their child.

3.2 It is impossible for one small group of individuals to be able to represent all these different groups. Patients who want to get involved with participation are often motivated to do so as a result of their own personal experiences. For example, the parents of a disabled child might be motivated to get involved to improve services for other disabled children but be less interested in committing personal time to improving services for another section of the community. Yet quite clearly LINk needs to be able to consider all aspects of local community health services.

3.3 The members of LINk should therefore not try to represent all patients views, but facilitate a process whereby patients’ experiences are fed back to the appropriate strategic committees and where necessary action taken to address problems. LINk should have the flexibility to co-opt individuals to work on particular projects. Voluntary organisations and community groups are often aware of any difficulties that their members have in accessing services. They can also provide a mechanism through which service users can feedback their experiences of services anonymously.
3.4 Though Patient Advice and Liaison Services (PALS) provide such a service, we are aware that many parents are reluctant to feedback negative experiences through this channel. Parents are often grateful for much of the help received and do not want to appear to be complaining about aspects of care that did not work well. Parents also often tell us they are worried that talking to PALS is seen as complaining and might have a negative impact on the way they and their child are treated when returning for future treatment. PALS could address this by being more proactive in seeking suggestions to improve services, carrying out a sample of patient interviews in different settings, as well as providing other mechanisms such as suggestion boxes to enable anonymous feedback about services. However, local groups also provide an easily accessible source of a particular patient group whose needs might not be picked up through other channels.

3.5 Contact a Family provides details of various national condition support groups through their directory. Many of these have local or regional groups who could provide contact with local families affected by long term conditions.

3.6 Very often within the NHS consultations are carried out when services are being closed, rather than to find out how services could be improved. Parents sometimes report that their views are being sought and then ignored. If patient participation is carried out poorly and is not seen as being effective then members of the public will not be motivated to get involved.

3.7 Health professionals are sometimes too busy to make time to seek patients’ views. They may also be reluctant, due to concerns that their patients will ask for services they cannot afford. Yet our experience of patient participation shows that solutions can often be found to problems through better understanding of individuals’ needs, without necessarily requiring needing extra funding. (Parent participation improving services for disabled children in health settings, 2005, published by Contact a Family).

3.8 Where patient participation is seen to work well in influencing how services are delivered, patients and carers are motivated to continue getting involved. Training is required to ensure Commissioners, members of LINk and local community groups understand how to make participation work effectively.

4. RECOMMENDATIONS

4.1 The LINks should:

— Build up contacts with local community organisations, and find out from them their concerns over health service provision.
— Understand the variety of approaches available to consult with patients and carers and what is required for participation to work effectively.
— Co opt individuals from the local community to work with them for specific projects which might be time limited.
— Provide practical support, including financial help, to assist groups in consulting with members and support patient representatives from these groups to report back their findings to commissioners and providers.
— Provide practical support so that parents, carers and patients are able to participate in this work.
— Identify suitably qualified individuals who can assist when consulting with young children who require a particular expertise.
— Ensure that all patient groups needs are being considered, including hard to reach groups.
— Report to the overview and scrutiny committees on how the process is working.
— Publicise to the local community how patients views have influenced the way services are delivered, to motivate members of the public to continue participating.

See attached page for diagram representing our vision for LINk.
Health Committee: Evidence

Overview and scrutiny committees

Specific services users: disabled people, mental health service users, elderly people, young people, parents,

Specific hard to reach groups: asylum seekers, BME groups, looked after children, youth offenders, travellers,

Voluntary organisations and community groups

Commissioners & providers

Participation manager/Administrator

Brilliant user led services

Feedback outcomes

Feedback outcomes

Vocal, able users

January 2007
Evidence submitted by Community Investors (PPI 128)

1. EXECUTIVE SUMMARY

1.1 Community Investors’ evidence is drawn from our individual and collective experience of playing an intermediate agency role in supporting local people, service users and groups to engage with a range of attempts by local and national government and health bodies to achieve patient and/or public involvement in health and social services and other decision-making, including regeneration. Community Investors has acted as a Forum Support Organisation to PPI Forums in North London since inception in December 2003 under contract to the Commission for Patient & Public Involvement in Health.

1.2 It is clear to us from our experience that:

— Effective patient and public involvement increases the likelihood that decision-making in health and social care will benefit users and communities
— Terms of reference for decision-making in health and social care should be developed to foster equity and trust among stakeholders
— Effective PPI requires independent PPI bodies and PPI support organisations, free from the conflicts of interest of providing health or social care services
— Those potentially most affected by proposed changes in the NHS should have their views and interests demonstrably taken into account before decisions are finalised
— Repeated changes in patient and public involvement structures absorb scant resources which could otherwise be used in improving patient care and public well-being, and if not evidently necessary can undermine trust and demoralise those involved, including staff in NHS and social services.

2. BRIEF INTRODUCTION

2.1 Community Investors is a strategic development agency established in 2001. We believe that local people, with their intimate knowledge of the needs of their communities, have a critical part to play if there is to be effective and sustained economic, social and environmental transformation. We work as far as possible at a strategic level; many of our activities are innovative and involve networking, support to others, acting as a third sector interface between government and community and making recommendations on policy and standards.

2.2 Community Investors has a diverse staff team with backgrounds in a variety of fields, including local government, the voluntary sector (including intermediary agencies) and social enterprise, largely within areas of high deprivation. Research is a critical part of our work and includes managing or undertaking studies of issues which matter to communities, producing briefings and discussion papers and helping to bridge the gap between academic researchers and local people.

2.3 Our evidence draws on our work in the field of user and public engagement and on our collective experience over many years, and addresses the following questions:

— What is the purpose of patient and public involvement?
— What form of patient and public involvement is desirable, practical and offers good value for money?
— Why are existing systems for patient and public involvement being reformed after only 3 years?
— In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

3. THE PURPOSE OF PATIENT AND PUBLIC INVOLVEMENT

3.1 Patient and public involvement (PPI) should ideally reflect partnership working to improve care and wellbeing. This should in turn help to foster a climate of greater equity and trust among stakeholders where the interests of and feedback from patients and/or public (whether any one of them is present or not) are demonstrably taken into account and thus more clearly planned for, including fulfillment of associated essential needs, such as transport and access to premises or advocacy.

3.2 Patient and public involvement in the new NHS, published by the Department of Health in 1999, is a valuable statement of what PPI can and should offer. “Only by involving local communities can we gain a better understanding of how local services need to be changed and developed. By creating greater local ownership of health services we can improve the quality and responsiveness of those services and reduce health inequalities,” states the foreword. Indeed “Working effectively in partnership with patients can also be of great benefit to the NHS. It delivers better results for individual patients and better health for the population.” This document contains useful pointers on ensuring that “patient and public partnership is genuine, not token, so that people at a local and national level, are fully involved in decisions both on their own care and on the way in which services are provided.”
3.3 Strengthening Accountability: Involving Patients and the Public: Practice guidance: Section 11 of the Health and Social Care Act 2001, published by the Department of Health in 2003, along with associated Policy guidance, is also helpful. Reasons cited to involve and consult include:

- Seeking the views of others and having mutual regard for them is an important element of planning.
- Services are designed and adapted to respond better to people’s needs.
- A consultation allows alternative proposals to be developed.
- It demands that proper time and thought is given to patient’s and the publics’ views on a proposal and ensures the development of an evidence base for important decisions.
- The experience of patients’, the public and local communities knowledge can be used to benefit others.
- Better decisions are made because more people’s views, perspectives and suggestions are heard.
- Major decisions are more transparent and the process for reaching them is understood.
- Trust is built between communities and the health service.

3.4 The health and social care system is complex, involving many interlocking strands and participants whose input is important if successful outcomes are to be achieved, not least patients and carers themselves. Well-intentioned initiatives announced by the Secretary of State or a Strategic Health Authority may not have the desired effects unless shaped by frontline experience and adjusted through feedback by those most intimately affected.

3.5 PPI can also be seen as an aid to performance management and improvement, enabling senior management or central government to check whether their instructions to frontline providers of care are being followed (for instance on access to GP services). Where there is an overlap of priorities (eg on hospital cleanliness) this can be of value, but it should be borne in mind that users and communities may have a different perspective on quality and access, and this should not be lost.

3.6 In particular, concerns raised through PPI Forums, Patient Advice and Liaison Services, Independent Complaints & Advocacy Services, Trusts’ own complaints mechanisms, Ombudsman’s rulings, Judicial Reviews and other legal proceedings, while often uncomfortable for the NHS, can be valuable not only in achieving redress for individuals but also in rectifying system errors and patterns of poor performance. While there are some people who project on to NHS and social care personnel their dissatisfaction arising from elsewhere, others who are unhappy about their treatment may have just cause. All too often, however, local people (especially those in poor health or who are not very assertive) find it difficult to get due recognition of and recompense for what has gone wrong, and organisations to learn from mistakes.

3.7 Regrettably, PPI is sometimes regarded as solely a presentational matter. For instance, deliberative events on service reconfigurations to fit in with the NHS white paper “Our health our care our say” are sometimes treated as part of a drive not only to fulfil legal obligations but also to convince local people that proposed changes are beneficial; any reluctance is assumed to spring wholly from lack of understanding and fear of change. It may be assumed that professionals have a complete grasp of all that is important. So when reasonable concerns are voiced, for instance that adequate community services will not be in place in time to cope with reduced capacity in the acute sector, bearing in mind population needs, these may not be properly heard. In considering changes to complex systems, it is helpful for these to be scrutinised thoroughly and from the perspectives of different stakeholders, and bearing in mind that gains in one area may be offset by losses in another. Meaningful PPI may seem to slow down the modernisation of the NHS, but is vital to maximise its benefits and minimise unintended negative consequences.

4. Forms of PPI: Desirability, Practicality and Value for Money

4.1 Following on from the points made above, PPI can be:

- systematic or arising from individual or collective reactions to a particular event they have observed or experienced which may have wider consequences;
- open-ended—enabling users, carers, local people and their representatives to make suggestions or discuss concerns—or based on a fixed format, for instance the patient survey;
- involving all who wish to contribute or just representatives, whether elected, volunteers or a random sample.

4.2 In our experience, a combination of methods and approaches can yield rich results. However it is important that all who might be profoundly affected by a decision (even if senior staff believe it will be beneficial) have an opportunity to comment if possible.

4.3 It is also important to bear in mind, in the words of Baroness Finlay of Llandaff in the House of Lords in 2002, “The independence of the view of patients is crucial. I cannot over-emphasise how vulnerable patients feel when they are ill. If they feel that they are complaining into an organisation on which they are
dependent for their care, they are terrified that there may be some backlash against them. Healthcare professionals ignore the need for an independent patient voice at their peril, because that is the safeguard in ensuring that we improve the standards of practice.”

4.4 While current policy emphasises the important area of PPI in commissioning, input on operational matters is also important. What might seem trivial to someone comparatively healthy may take on huge significance to people who are extremely ill, frightened, confused or in pain. Moreover, serious problems can arise when NHS staff and managers are not attentive enough to the practicalities of delivering an excellent service. The increasing involvement of diverse contractors means that new complexities affecting patient and public access and care are likely to arise.

4.5 The strengths of patient and public involvement forums include their ongoing relationship with trusts and local patients, so that they can pick up and track progress, helping NHS managers and clinicians to evaluate whether their attempts to deal with a problem have been successful and identify alternative approaches if necessary. Continuity and the development of mutual understanding, while maintaining a critical distance, are important. Forums can also work more flexibly and quickly and with greater patient focus than larger statutory bodies.

4.6 It is helpful for those seeking to represent user and public interests to be committed to the highest standards of public service and equality, especially since experiences of health care and prevention can be so diverse. Inclusive methods should also be used, as discussed in numerous documents.

4.7 One approach which we have found useful—and which is particularly relevant in the context of an emphasis on multi-professional and multi-sectoral partnership working—is the development of equity terms of reference. If, for instance, different “sectors” are represented on a joint planning/commissioning body (eg NHS, local authority, users/carers/voluntary sector), a quorum in each “sector” must be achieved to enable certain decisions to be made. Stakeholders who wish their own concerns and interests to be advanced are thus required to listen to and negotiate with others, and take other perspectives into account. After a while, this can foster a culture in which partners come to consider issues from different angles even before they discuss these with other “sectors”. We can give further information on application, if helpful.

4.8 Changing organisational and professional culture to foster awareness of the need for PPI, and the skills to make it effective, has been mentioned in many documents, and remains vitally important. Training is part of this, so that PPI is seen as the business of all involved in health and social care, though specialists will continue to play a necessary part. Otherwise, even if organisations manage to meet their legal obligations, in practice decisions will continue to be made without adequate input from patients and the public and due consideration of how they will be affected.

4.9 Central government guidance and the legal framework are also important in nurturing adherence to good practice in PPI. Unfortunately at present, because of resource pressures and a fragmented approach to efficiency which focuses on individual components rather than whole systems, cost-cutting measures are sometimes being implemented without due consideration of potential negative consequences: just as medication may have undesired side-effects because of the complexity of the human body, so too may service changes in the context of a complex system. Moreover, non-executive directors and board members are being continually reminded of their duty to stay within budget, but less emphasis is placed on their responsibilities for ensuring adequate standards for all and safeguarding equality and human rights for those with health-related needs. Ensuring meaningful PPI, and continuing to remind professionals of the need for a holistic person-centred perspective where different sectors do not try to shunt costs on to others (including patients and carers themselves) but rather cooperate for the best outcomes, are important.

5. REFORMING EXISTING SYSTEM AFTER ONLY THREE YEARS

5.1 The current PPI system has demonstrated valuable successes as well as shortcomings, and it seems to us that—whatever the pros and cons of the proposed reforms—many familiar with the current system are not convinced of the need for another major upheaval after a short time, as opposed to improving the workings of current arrangements.

5.2 When community health councils were abolished against strong opposition, the government insisted that, because “forums are basing themselves on the services of a particular trust, they will be able to focus very much on the concerns of patients using those services. That will be a great advance” (to quote Lord Hunt in 2001), though linking mechanisms were acknowledged as necessary. Without wishing to revisit the controversy over the abolition of CHCs, it has not been made clear why the government has changed its position completely (rather than, say, emphasising the existing responsibility of forums to cooperate on matters of joint concern and the relevance to commissioning matters and patient pathways).

5.3 Again, with regard to the effectiveness of the existing PPI system, it is not clear why strategic health authorities (SHAs) have not generally been doing more to monitor the implementation of the guidance in Strengthening accountability and utilise the Performance Improvement Framework for Patient and Public Involvement in the NHS, also published in 2003, in particular seeking “Documented evidence of liaison with PPIFs and evidence that feedback has contributed to service planning and delivery”. Indeed, SHAs themselves have not always fully demonstrated their compliance with Section 11 and shown how user and public input has helped to shape their decisions. Rightly or wrongly, the impression has perhaps been created...
that the integration of PPI into decision-making has been unevenly promoted at the higher levels of the NHS, despite the work of a number of champions, and this has made the task of PPI forums and local NHS PPI leads more difficult.

5.4 It is also unfortunate that the impression may have been created that ministers and civil servants take Parliament’s assent to the proposed legislative changes to PPI for granted, and are asking for time and money to be invested in the new system before it has been properly debated, refined and finalised.

5.5 Frequent system reform comes at a price, especially since some time is required for the glitches in any new set-up to be removed and effective working achieved. At any rate, if LINks are to be created only to be reviewed a few months later and abolished in two-four years, as would seem likely if current patterns continue, this would be unhelpful, and further undermine confidence in the efficacy of supposed improvements to PPI structures.

6. WIDER PUBLIC CONSULTATION AND THE SCOPE OF SECTION 11

6.1 Proposed legislation suggests that the duty to involve and consult should be confined to “significant” proposals. It has become apparent that what might not seem significant to a senior manager may be perceived and experienced differently from the perspective of a service user or carer.

6.2 The point has been made elsewhere that, where it is unclear whether wider consultation is needed, forums should be able to advise trusts on this, if kept informed at an early stage on service proposals. Obviously there will be certain matters such as major changes to how and where services are delivered on which users and carers should be consulted, and wider reorganisations on which the local public’s views should be sought.

6.3 Whatever system for PPI is ultimately agreed, it is important that, as stated in “Strengthening Accountability” guidance “Services are designed and adapted to respond better to people’s needs”, “proper time and thought is given to patient’s and the public’s views”, there is “an evidence base for important decisions”, “Major decisions are more transparent” and “Trust is built between communities and the health service.”

Timothy Modu
Chief Executive, Community Investors
10 January 2007

Evidence submitted by Countess of Chester Hospital PPI Forum (PPI 87)

1. What is the purpose of patient and public involvement?
   — To give a patient perspective
   — To improve services
   — To represent the interests of patients and the public in the NHS decision making processes
   — To champion equity and choice

2. What form of patient and public involvement is desirable, practical and offers good value for money?

   The existing structure is now well established and working effectively in many, many areas. Rather than change it yet again it would be more appropriate to give Forums a period of stability and continuity so that they can focus on their role rather than fighting for their future.

3. Why are existing systems for patient and public involvement being reformed after only three years?

   Why indeed? To start again would be a waste of time, money, resources and the goodwill and experience of forum members and staff.

4. How should LINks be designed, including:
   — Remit and level of independence—Independence from the local NHS is a vital requirement.
   — Membership and appointments—Existing mechanisms are adequate.
   — Funding and support—Existing levels of funding and support could be adequate if they are used more effectively and concentrated on supporting grass roots forums rather than an unnecessary and costly central agency.
   — Areas of focus—It is vital that LINks continue the non-political tradition of PPI Forums and CHCs. For individual forums the focus should be overwhelmingly local.
   — Statutory powers—Continuation of the existing powers and rights (rights to information, visits and inspections etc) is essential if the LINks are to have teeth.
   — Relations with local health Trusts—One of the successes of PPI Forums has been the development of specialist forums (mental health, ambulance, oncology and acute trusts) with a dedicated focus. LINks based on geographical areas might lose this expertise and experience.
— National coordination—for national and regional issues there needs to be some means to co-ordinate a wider voice. ACHCEW is a good model.

5. How should LINks relate to and avoid overlap with:
   — Local Authority structures including Overview and Scrutiny Committees—Existing structures work well and ensure a non-political element to the scrutiny process. LINks should be patient-centred and OSCs should have a more strategic element so there should be no conflict or overlap in roles.
   — Foundation Trust boards and Members Councils—FT boards can specify who they appoint. LINks members should follow the lead of PPI Forums and be drawn from diverse sources. LINks can be more independent as they do not have the burden of corporate responsibility.
   — Inspectorates including the Healthcare Commission—Existing rights to report and “call in” are adequate.
   — Formal and informal complaints procedures—Help and assistance with NHS Complaints procedures should be provided by a dedicated service of paid professionals—preferably to a higher standard than current ICAS arrangements. LINks will, however, need access to data on complaints. This has never been provided to PPI Forums in any meaningful format.

6. In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

Existing Section 11 requirements on NHS bodies must remain in place for any substantial variation in the pattern of services provided by the NHS locally. Additionally, this should be extended to cover the redrawing of access criteria—this has been used by many PCTs as a “stealth” method of rationing.

Countess of Chester Hospital PPI Forum
January 2007

Evidence submitted by County Durham and Darlington Acute Hospitals PPI Forum (PPI 4)

EXECUTIVE SUMMARY

This submission has been written by David Taylor-Gooby, Forum Coordinator for the PPI Forum for the County Durham and Darlington Acute Trust.

David Taylor-Gooby works for the Forum Support Organisation (FSO) which supports the Forum. As from January 2007, however, he will work directly for the Commission (CPPH). David was previously a Lecturer and taught the Health Studies Degree, so has some knowledge of the NHS. He also has some experience of local government, and has sat on a Health OSC subcommittee.

SUMMARY

(i) PPI must be seen to be independent and effectively raise the concerns of the public to the NHS, which must be obliged to respond.

(ii) Resources need to be concentrated on the “front line”, but for effective investigations and projects to be done there needs to be a dedicated core of volunteers who will take the time to carry them out.

(iii) Forum members are concerned that the experience and expertise built up by Forums may be lost. There is a need to publicise our activities more and recruit new members. Forums must be seen to be independent of local government. There needs to be a Forum to relate to Acute Trusts.

(iv) Points which need to be made about LINks:
   — Must be seen to be independent of local authorities.
   — The public must be able to make their concerns made to LINks.
   — There needs to be a core of dedicated volunteers to carry out projects.
   — LINks will need adequate support to be effective.
   — Its area of focus should include the Acute Trust.
   — It will need powers for selected volunteers to visit NHS premises.
   — PPI needs to establish a relationship of “consensual scrutiny” with Trusts.
   — Large amounts of money should not be spent on national coordination.
(v) Conclusion

— PPI must be seen to be independent both of Trusts and the Local Authority.
— There must be ways in which it can respond to the concerns of the general public.
— There needs to be a team of dedicated volunteers to carry out effective investigations.
— Effective scrutiny of Acute Trusts should not be neglected.
— There needs to be adequate support, but excessive resources should not be spent on national coordination.
— Volunteers do need the right to visit Trust premises, but there does need to be proper controls on this.
— Existing Forums do need to publicise their activities.

The Forum wishes to submit some evidence of its activities which are relevant to these terms of reference.

1. The Forum has been established for three years, and has twelve active members. There has been some “churning” over the years, with new members joining and others leaving because of personal circumstances, usually illness. Many of our members, because they are involved with the hospital trust, have long-term conditions. A dedicated team has emerged who have established a “team spirit” and work together. The Chair has been effective and provided good leadership. The Forum has undertaken various projects, but I should like to draw attention to two:

2. “Food for Thought” an investigation into catering at the main Trust sites. This looked at the various catering provided and the reaction of patients. Forum members visited all the main sites and actually tried the food themselves. As a result recommendations were made to the Trust, particularly about ensuring patients ate their food, and using local suppliers. We set up a working party with them, which has made some progress.

3. Stroke is a Medical Emergency. This was a one day conference drawing together representatives of Primary Care Trusts, GPs, PPI Forum Members, and workers from the Acute Trust to consider the whole issue of prevention, treatment and after care for Stroke Victims. The issue was raised by members of the public concerned about the low priority given to both the treatment and aftercare of Stroke victims, and was influenced by the recent Public Accounts Committee Report on Stroke and its effects, and how more effective prevention and treatment could save the country a considerable amount of money. The Conference drew people from various sectors of the Health Service and the voluntary sector who do not normally talk to each other. The Forum members intend to publicise the results widely, and campaign on the issue.

4. Both these projects were the result of concerns brought to us by the public, and could not have been organised without a dedicated team of Forum Members doing the legwork. Both have been recognised by the Acute Trust as important and influential pieces of work. I now intend to deal with the specific issues:

(i) The purpose of public patient involvement is for issues to be raised independently by members of the public which can then be investigated and proposed to the NHS. The NHS must then be obliged to engage in a dialogue to try and make some progress with them. This works best when there is mutual confidence and the Forum and Trust work together. The two projects outlined above are good examples of this.

(ii) Forum Members would be the first to acknowledge that value for money could be improved, and that more members of the public need to be involved. For effective projects to be done, however, there needs to be a small core of people willing to organise them, which a larger network might not be able to do. Neither of the two projects outlined above would have happened without the commitment of volunteers. The wider public can be consulted through conferences, or visits to community organisations as our Forum has done. There has been duplication in the management of Forums between the Commission and FSOs, and Forum Members would heartily agree that there is less need for national coordination and infrastructure, and more resources for their front-line work. The Conference, for example, was very successful and we have been asked to organise more, but they are very resource-intensive. The actual day-to-day operation of the Forum does not cost very much.

(iii) Forum Members are concerned that the existing systems are being reformed after three years. There is a need for streamlining the work of the Commission, but existing Forums, which have now developed a good sense of being a Team, and a good track record of projects and a knowledge of what works and what does not, should not be. They do need to publicise their activities more, and communicate more with the general public, but this is a problem faced by many organisations, including local authorities. A further concern of members of the Acute Trust Forum is that the emphasis of LINks will be on Commissioning and the work of the PCT, and that our concerns about the Acute Trust will be sidelined. The Forum has built up a good relationship with the Trust which seems keen for us to continue after they have achieved Foundation Status. The strong point of the Forum is that it is independent of both the Trust and the Local Authority. The new arrangements might give the impression of being too closely associated with the Local Authority which could upset some members who value their independence.
If LINks is established, members would like to see the following points taken on board:

- It must be seen to be independent of the Local Authority.
- There must be a mechanism for the public to take their concerns to LINks.
- LINks will need to have a “core” of committed people who meet regularly and are willing to undertake projects, without getting bogged down in committee procedures.
- LINks will need adequate support so that it can undertake research which will be taken seriously.
- Its area of focus should include the Acute Trust.
- It will need Section 11 powers to require Trusts to respond, and to work jointly with it. An important power which the present Forums have is the right to visit Trust premises, but in a wider, more diffuse organisation like LINks this would have to controlled. (People have to be CRB checked).
- PPI works best if there is a relationship of “consensual scrutiny” with Trusts.
- There may be a need for national coordination, but there is not a strong case to spend large amounts of money on this.

5. Conclusion

Members of the County Durham and Darlington Acute Hospitals Forum feel that much good work has been done since they were established, and are concerned that the expertise and sense of teamwork they have established may be lost. In particular they wish to make the following points:

- PPI must be seen to be independent both of Trusts and the Local Authority.
- There must be ways in which it can respond to the concerns of the general public.
- There needs to be a team of dedicated volunteers to carry out effective investigations.
- Effective scrutiny of Acute Trusts should not be neglected.
- There needs to be adequate support, but excessive resources should not be spent on national coordination.
- Volunteers do need the right to visit Trust premises, but there does need to be proper controls on this.
- Existing Forums do need to publicise their activities.

David Taylor-Gooby
County Durham and Darlington Acute Hospitals PPI Forum
14 December 2006

Evidence submitted by Craven, Harrogate & Rural District PPI Forum Group (PPI 12)

1. The purpose of patient and public involvement is to ensure that local people input their views into strategy planning and delivery of their local health service.

2. A secondary purpose is to ensure that patients receive appropriate information regarding their NHS organisations.

3. There seems to me to be no reason for reforming the existing PPI Forums. PPI Forums were set up to fail; they were provided with little or no appropriate support. CHCs had experienced CHC Officers who were familiar with local and national issues, and the experience of our Forum the form support organisation did little more than read the rule book and book a room occasionally, and take minutes which were often illiterate, little or no support or guidance was given to the Forum regarding the NHS.

4. Over a period of some three years, members who were dedicated to their local NHS acquired considerable experience. A number of exemplary activities were carried out, for example, the PPI Forum worked on a advisory questionnaire for patients suggesting the questions that patients could ask of their healthcare professional in appropriate circumstances. The Forum also contributed to work on the PILS leaflet in pharmacies, to providing knowledge of the NHS for those whose first language was not English, and worked closely with its primary care trust and was consulted on matters of change and where possible consulted the public.

5. The membership was consistently lower than it should have been, there was little or no training, but in its third year, where members are acquiring real ability to scrutinises an input, it is being abolished.

6. I personally do not see the point of LINks as it has no teeth as constituted at present, it will simply be a “talking shop” and I think that very few people who are interested in doing something in their local community will be prepared to serve. If it is to be reinvented, it should reinvented with a statutory powers
of PPI Forums, or alternatively the Local Authority Scrutiny Committees should be reconstituted, given much greater officer support than at present, and should broaden their overview. An alternative is that Forums become a local arm for the Healthcare Commission.

Craven, Harrogate & Rural District PPI Forum Group

January 2007

Evidence submitted by Diabetes UK (PPI 100)

Diabetes UK is one of Europe’s largest patient organisations. Our mission is to improve the lives of people with diabetes and to work towards a future without diabetes through care, research and campaigning. With a membership of over 170,000, including over 6,000 health care professionals, Diabetes UK is an active and representative voice of people living with diabetes in the UK.

1. **What is the purpose of patient and public involvement?**

   1.1 Patient and Public Involvement is integral to achieving responsive, relevant healthcare services for all patients. Involving users in local planning and decision-making is the only way to create a health service built around the needs of those who use the service, rather than the needs of the system. User involvement supports services and practitioners by providing them with access to information about the real experiences of the people who use the services. Involvement of users in the design, planning, delivery and monitoring of local diabetes care services is central to achieving the NHS Plan vision, to “reshape the NHS from a patient’s point of view”1 It is essential for people with long-term conditions to feel empowered as effective control relies on self-management for good clinical outcomes. People can only self-manage in the context of services that work for them. Therefore, the needs of people living with diabetes should be central to every element of local decision making to meet political aspirations, improve legitimacy and ultimately to ensure a better service.

2. **What form of patient and public involvement is desirable, practical and offers good value for money?**

   2.1 Involvement of people with diabetes and their carers should be at every level of decision making:— Strategic, operational and practical. It is about listening, openness and dialogue between those managing, providing and using the service. Involvement is essentially about relationships. Activity that enables dialogue between all stakeholders has to be included in agendas,2 through informing, consultation and partnerships.3 Representation and supported involvement of people living with diabetes, for example through Diabetes Networks, PCTs and similar structures, provide mechanisms for considered, comprehensive and informed views about how needs can be appropriately met.4 The User Representative role has been developed to ensure the voice of people with diabetes is present to ensure diverse and broader knowledge, experience, and perspectives are represented. User Representatives are there to support the process of engagement but are not ultimately responsible for it. Wider consultation should also be undertaken.5

   Involvement is needed to influence local service delivery to improve:
   - partnership working through building and sustaining relationships
   - accountability and legitimacy for decisions made
   - relationships between the users and staff with clear expectations6
   - feedback and evaluation about service provision to help improve and shape future provision
   - empowerment of communities and reduction of inequalities7
   - experiences of those who use services leading towards improved health outcomes.

   2.2 The process of involving people with diabetes in planning diabetes services should be resourced, monitored and evaluated. This is to ensure mechanisms for involvement are working effectively and that changes to diabetes care have been made that reflect the input of service users.5

   2.3 People with diabetes are central to all aspects of the work of Diabetes UK, making us a leader in the field. We have a strong representation in our governance structure of lay representatives, with 60% making up our Advisory Council. The Advisory Council is involved in shaping the organisation’s strategy and elects the Board of Trustees. Other forms of user involvement include a secure online discussion site where a wider number of users can be consulted, form focus groups, and take part in surveys, all of which inform a variety of the organisation’s work streams. We have a reader’s panel to provide feedback on the content of our membership magazine, Balance and people with diabetes also sit on our research committee and express their opinions on the value of research to people with diabetes. In the case of borderline decisions, it’s the lay members of the Committee who have the final say because it’s the money of members of the charity that funds research. Members of our voluntary groups also undertake various activities including providing peer support to others with diabetes and their supporters, and disseminating Diabetes UK information.
2.4 Diabetes UK receives funding from the Department of Health to implement a service user involvement project, which has been running for four years. This project aimed to support the implementation of the National Service Framework for Diabetes, with regard to users becoming directly involved in the planning, development and delivery of local health services via Diabetes Implementation Groups and Managed Diabetes Networks. Diabetes UK has trained 167 user representatives at 19 training days held during the course of the project.9

2.5 Diabetes UK has also developed guidance for PCTs regarding how they can effectively recruit and support User Representatives, which can be accessed at http://www.diabetes.org.uk/professionals/Shared_Practice/Care_Topics/User_Involvement/User_Involvement_-_Care_Recommendation/.

2.6 The National Diabetes Support Team (NDST) has recently announced that it is funding a new project to be carried out by Diabetes UK in partnership with London Metropolitan University. The aim of the work is to ensure that people with diabetes are involved in everything that impacts on their health care. They will be able to contribute to policy development at the Department of Health and also at a local level to diabetes networks and service delivery. It will focus on engaging “hard to reach groups” eg ethnic minority communities, as well as children and young people and their carers/parents. The new work will, among other things, link with existing user involvement organisations, collate examples of good practice and work towards providing training for healthcare professionals.

3. Why are existing systems for patient and public involvement being reformed after only three years?

3.1 Diabetes UK responded to the consultation “A Stronger Local Voice” published by the Department of Health which aims to create a stronger local voice in the development of health and social care services. In our response we recognised that significant improvements need to be made to enable the general patient and public to be involved in local service delivery. We expressed our disappointment that existing routes for involvement are to be abolished and new ways proposed, rather than attention being put into strengthening and adapting those already in existence. We have had feedback from users and staff that they find the NHS and its involvement mechanisms confusing. More changes will make it even more difficult to encourage and support users to have their say.

3.2 These new proposals will be unsettling for a large number of users currently involved and could result in a feeling of disenfranchisement of those who are already closely involved in Patient Forums. Appropriate and supportive communication, valuing the input already put into developing Patient Forums is absolutely necessary for local engagement and involvement to increase.

3.3 The key areas to be addressed through the new structures are:

— The skills, passion and knowledge of users already working with PCTs and SHAs must be retained for the newly proposed systems to work.
— Careful and widespread communication about systems, funding and support opportunities needs to occur across existing community and local voluntary groups, particularly focusing on what their role is, how it works and how people can feed into them.
— A key role of LINks should be to network and engage with existing community and voluntary groups to facilitate the exchange of views and comment.
— Flexible opportunities for being involved need to be developed. Many people are keen to be involved in local service developments, but prefer not to attend meetings.
— Emphasis must be placed on training practitioners and managers working directly with involved users and for staff and elected members who will be the recipients of user views.
— Planning, commissioning, monitoring and evaluation of diabetes services must involve volunteers, user representatives, carers, healthcare professionals and campaigners directly affected by diabetes. Models of good practice already exist where managed diabetes networks, involving specialist, primary and community staff working alongside people with diabetes are planning and developing local diabetes services.
— Efforts must be focused on proactively seeking and benchmarking patient access and experiences. Information to inform service delivery and choices must be more widely accessible and support to understand it made available.

4. How should LINks be designed?

4.1 Remit and level of independence

4.1.1 LINks should contribute to the agenda allowing people with diabetes and other users to input into services. The work should support the implementation of the National Service Framework for Diabetes by facilitating users direct involvement in the planning, development and delivery of local health services via Diabetes Implementation Groups and Managed Diabetes Networks.
4.2 Membership and appointments

4.2.1 Sound governance arrangements need to be established to ensure that LINks are managed appropriately and to ensure that all members of the local community wishing to be engaged in health service planning, commissioning and monitoring/regulation are able to do so. Recruitment of members needs to be supported by a transparent system detailing how implementation will happen, sustained and evaluated. Particular efforts should be made to ensure all sections of the community are represented. Transparency will be supported by having elected boards to ensure consistency with other policies for accountability and representation with Foundation Trusts.

4.2.2 Clear role descriptions should be developed and be the basis upon which individuals are informed of what they have to do and the means by which they are recruited. In order to ensure accountability of management and governance structures, local area elections should be considered, where individuals wishing to be involved in the management and governance structures are chosen by the entire local community on the basis of their case made for standing. Paid staff will be required to undertake the administrative and management functions to ensure that the LINks are successful.

4.2.3 As well as commissioners being required to respond to the community and provide feedback on the results of consultations, PCTs and providers should also be required to put in place user involvement strategies defining what and how they are going to involve patients and the public. How strategies are communicated to the local community should depend on local circumstances. For example, circulated to all houses in the local community, seeking comment, feedback and expressions of interest about how they could be involved, and through local voluntary and community groups. Involvement in LINks should not be solely based on membership as not all people wanting to get involved will want to “join”.

4.2.4 Past experience has shown that services can find it difficult to involve black and minority ethnic communities, so it is important that there is a willingness to go out to meet individuals. For example: in community centres, places of worship, festivals and shopping areas; healthcare workers, especially link workers and those from the same ethnic background, should always be drawn on for their expertise and contacts; advertise the position/s in places people visit on a regular basis, such as shops, temples and mosques. Diabetes UK has developed a toolkit designed to help engage ethnic minority communities http://www.diabetes.org.uk/campaigns/index.html.

4.2.5 The following principles should be applied in the development of new systems:

— Initial information should be provided about what is involved, what they are being asked to do, availability of administrative support and reimbursement of expenses. Diabetes UK recommends that all out of pocket expenses should be covered ie travel, childcare costs and carer costs. Strong consideration should also be given to funding users and members time to achieve significant engagement.

— Various methods can be used to attract people living with diabetes, which include for example:
  — ask healthcare staff to promote the opportunities for involvement;
  — ask existing user representatives to inform friends, families and colleagues;
  — posters in GP surgeries, hospitals or pharmacies;
  — mailings to all those living in a neighbourhood, perhaps through the electoral register;
  — contacting local voluntary groups or organisations eg one of Diabetes UK voluntary groups or networks;
  — advertising in community centres, Patient Advice and Liaison Services (PALs), and local press;
  — contacting national organisations, such as Diabetes UK, Voluntary Action Councils or disability groups who may be able to promote activities in communication channels; and
  — holding public meetings to share information, answer questions or consult on current services and future planning. These meetings offer the opportunity to find people who may be interested in getting more involved.

4.3 Funding and support

4.3.1 There needs to be recognition from the Department of Health that investment is needed to enable user involvement. This needs to be done from two perspectives; there needs to be support and training for the users and also support and training opportunities built in to enable healthcare professionals to listen to the users. LINks need to be provided with knowledge and skills to involve users and how to value users view.

4.4 Areas of focus

4.4.1 Obviously we would like a focus on diabetes services specifically. However, our User Representatives have fed back to Diabetes UK the importance of taking a holistic approach to service design. Diabetes, as a long-term condition, has many similarities with other conditions such as heart disease, stroke, asthma, cancer. These similarities include exercise, diet, lifestyle, counselling, support on diagnosis, patient self help and education. Whilst there are differences in the actual content that require a specialist approach, there could be a generic process and approach. For example, a NHS team funded a gymnasium
specifically for their diabetic patients but that was only available part time. If this had been set up as a general resource for others to use, then GPs could refer more patients with other needs to the unit, thus allowing the resource to be used more efficiently and available to help more people.

4.5 Relations with local health Trusts

4.5.1 We welcome the requirement that NHS trust providers and PCT commissioners need to increase meaningful engagement. However, the guidance does not currently specify how this can be done. Emphasis must be placed on identifying and engaging with the systems and groups already in existence. Specific requirements need to be put in place detailing how and who PCT commissioners consult with to commission and develop new and existing healthcare services. Planning, commissioning, monitoring and feedback of diabetes services must involve volunteers, user representatives, carers, healthcare professionals and campaigners directly affected by diabetes and using the services. Systems will need to be put in place to ensure involvement and support of users focused on specific conditions such as diabetes, as well as around functional and generic healthcare delivery issues, to ensure accountability. Models of good practice already exist where managed diabetes networks, involving specialist, primary and community staff working in partnership with people with diabetes (user representatives and champions), are planning and developing local diabetes services. Diabetes UK provides detailed guidance and practice examples to users and those working in the NHS www.diabetes.org.uk/sharedpractice. It is these established networks that should be leading and advising on the commissioning and monitoring of appropriate services, with strong involvement from people with diabetes.

5. How should LINks relate to and avoid overlap with:

5.1 Local Authority structures including Overview and Scrutiny Committees

5.1.1 The plans for LINks to establish specific relationships with OSCs will we think provide greater accountability, however concerns exist about how closely all OSCs currently work with PCTs and healthcare professionals to ensure adequate patient and public involvement in healthcare. The creation of stronger links between health and social care is essential for improving the integration of health and social care. OSCs need to strengthen their links with PCTs and proactively monitor services for specific groups. The National Service Framework for diabetes sets clear standards of care for people living with diabetes and OSCs need to ensure that these standards are being delivered in all areas.

5.2 Inspectorates including the Healthcare Commission

5.2.1 The DH’s consultation document states that users will be more involved in regulation and inspection bodies and processes. However, it does not state how this will happen. We welcome the commitment to measure the performance of user involvement processes and look forward to commenting on the criteria developed to assess against national standards. In order to strengthen the voices of those living within local communities efforts must be focused on proactively seeking and benchmarking patient access and experiences. The Healthcare Commission User survey of access and views of people with diabetes will provide a good indicator to compare across local health areas. Diabetes UK has worked with Dr Foster to monitor the quality of diabetes care provided by PCTs in England comparing this to the experiences of and access reported by people with diabetes. The “Your local Care” benchmarking tool can be found at www.drfoster.co.uk/websites/objectlist.aspx?w=17. This tool, alongside Diabetes UK’s annual diabetes state of the nations report provides a means of benchmarking the quality of care nationally to inform commissioning processes and regulation to monitor if people with diabetes are receiving the care they should expect.

5.3 Formal and informal complaints procedures

5.3.1 Information about how to complain must be easily accessible. Users must be given information about what services to expect. Mechanisms should be in place about services to capture views of those who may not use traditional complaints systems. Systems should be in place to feed complaints about policy guidance back in at the local level so that these can be addressed locally as well as nationally.

6. Conclusion

6.1 Diabetes UK welcomes further advances towards putting in place structures to give patients and the public a greater say in the way that their health care is delivered. These structures must build on the successes of many Patient Forums but must also reach out to communities that have proven harder to reach in the past. Resources must be provided to ensure that representatives, managers and healthcare professionals are trained to communicate, listen and understand how to engage effectively using these new structures and there needs to be effective and ongoing monitoring and feedback systems in place.

Claire Francis
Public Affairs Manager, Diabetes UK

10 January 2007
REFERENCES

Evidence submitted by the Disability Rights Commission (PPI 137)

1. INTRODUCTION AND OVERVIEW

1.1 The DRC submits the memorandum following the Committee’s publication of the terms of reference for its inquiry into patient and public involvement in health services.

1.2 There are 10 million disabled people in Great Britain with rights under the Disability Discrimination Act including people with physical and sensory impairments, mental health problems, learning disabilities and long-term health conditions such as cancer and HIV/AIDS. But the Department of Health white paper “Our Health, Our Care, Our Say” reported in 2006 that not all disabled people have their needs met well by health services. We used our powers under the DRC Act to undertake a formal investigation into primary health services for people with learning disabilities and/or mental health problems which reported in September 2006 (“Equal Treatment: Closing the Gap”) that health services were not meeting the requirements of the DDA with regards to these two groups of disabled people in particular.

1.3 We believe that through the better inclusion of disabled people in patient and public involvement schemes, health services could better plan for and meet the needs of disabled citizens. “Nothing about us without us” is a mantra which may be familiar and explains itself, but without adequate inclusion of “experts by experience” services will not understand or meet the needs of all users.

1.4 We submit this memo as an expression of interest in providing fuller information if required by the Committee. As such, we have not answered all questions or gone into comprehensive detail on each question the terms of reference proposed.

2. What is the purpose of patient and public involvement?

2.1 The DRC believes that patient and public involvement should focus on service improvement. We have provided guidance on the inclusion of disabled people in the delivery of Disability Equality Schemes that many public authorities (including NHS Trusts) were expected to produce by December 2006. Evidence shows that health services do not currently meet disabled people’s needs. This must improve and Disability Equality Schemes are one means to achieve this requiring disabled people’s continued involvement. This could benefit patient and public involvement schemes and health services more generally.

14 http://www.drc.org.uk/employers_and_service_provider/disability_equality_duty/meeting_the_duty/involving_disabled_people.aspx
3. **What form of patient and public involvement is desirable, practical and offers good value for money?**

   3.1 The DRC supports effective involvement—ie that which has clear structure and purpose for involvement and can deliver improvements to health services for all citizens.

   3.2 There are various schemes to involve disabled people and other citizens in local service improvements: the Department of Health in England has a commitment in “Improving the Life Chances of Disabled People” (2005) to provide a local Centre for Independent Living in every local authority by 2010 for example. A coherent joining-up of such schemes could offer better value for money.

4. **Why are existing systems for patient and public involvement being reformed after only 3 years?**

   4.1 The DRC supports better systems for delivering real improvements for service users and their families.

   4.2 Existing systems have not provided the improvement in services disabled citizens require. We hope that new systems will better facilitate disabled people’s involvement. This is particularly important as our discussions with the Department of Health have revealed that disabled people form one in five of the working age population but one in three health service users. Over-representation as service users is not reflected in involvement schemes which have not secured improvements to services that disabled people require.

5. **How should LINks be designed, including:**

   — Remit and level of independence.
   — Membership and appointments.
   — Funding and support.
   — Areas of focus.
   — Statutory powers.
   — Relations with local health Trusts.
   — National coordination.

   5.1 The DRC believes independent LINks with representatives of local disabled people and their organisations with adequate funding and stipulated areas of work are desirable to drive service improvements and assist services in meeting legal requirements of the Disability Discrimination Act (DDA) 1995 as amended in 2005.

6. **How should LINks relate to and avoid overlap with:**

   — Local Authority structures including Overview and Scrutiny Committees.
   — Foundation Trust boards and Members Councils.
   — Inspectorates including the Healthcare Commission.
   — Formal and informal complaints procedures.

   6.1 The DRC believes that appropriate networking between LINks and local authorities will deliver better results. This will be especially appropriate following plans to introduce the joint commissioning of health and social services as outlined in the “Our Health, Our Care, Our Say” white paper last year.

   6.2 We also think co-ordination between national inspectorates, complaints procedures and LINks could ensure that involvement is not tokenistic but designed to deliver real improvements with “expert” citizens and service users understanding the full range of health service responsibilities and functions.

*Neil Coyle*
Disability Rights Commission

*January 2007*

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**Evidence submitted by Dr Foster Intelligence (PPI 125)**

Our response is based on our experience in a number of key areas:

— Working with three quarters of NHS acute trusts, in particular providing information on referral patterns, efficiency and quality.
— Managing campaigns to communicate health messages, including focusing on particular at risk or vulnerable groups.
— Producing information about healthcare providers for the public.
— Primary research with members of the public, for example, in relation to the configuration of services.
— Thought leadership and policy research in relevant areas.

We very much welcome the committee’s initiative to examine the issue of patient and public involvement. One of our key observations from our extensive experience in working with the NHS is that it has a long way to go before it succeeds in putting patients at the heart of the system.

The debate around patient and public involved has become sterile. It has generated an industry of its own—including its language and a bureaucracy. “Involvement” has become an end of itself, rather than an integral element of the delivery of health and healthcare. On the whole, the existing patient and public involvement machinery has failed and alienated those its success depends on: patients and frontline staff, through inadequate or misguided consultation, jargonistic language and resource intensive processes.

NHS organisations, commissioners and providers, need to develop their understanding of their “customers”, those that they are trying to keep well, or who need health services. Firstly, they need to improve their use of existing sources of data, such as that routinely used by the market intelligence teams in other service providing industries. Using consumer lifestyle information, linked to health data, provides a powerful source of insight into populations, their behaviours and preferences. Understanding populations in this way, allows health organisations to improve public consultation and engagement, because they understand who they are involving and why.

Secondly, the NHS needs to improve the feedback they receive from their customers and act on it to improve services. Hospitals and GPs are required to collect feedback on an annual basis which provides no meaningful insight into service delivery. Providers need to collect, analyse and act on data systematically. Commissioners need to ensure that evidence of feedback from patients is built into contracts and regularly monitored.

The future system needs to redefine the language and case for patient and public involvement. It must avoid structures which set it apart from the commissioning and delivery of health services, if it is to deliver services which meet the needs and expectations of those who use it. The current system relies all too often on one board member or an individual within an organisation rather than promoting genuine cultural change.

There are organisations which are working in innovative ways to engage their local communities and patients. Examples we are aware of include:

— Brent Teaching PCT—Local teenagers were recruited to distribute sexual health messages and a voucher system for free condoms to tackle increasing rates of teenage pregnancy and sexually transmitted infections. Reactions to the campaign were overwhelmingly positive amongst the target, teenage group. As one girl told the project team: “I don’t want sex education from some posh woman from Surrey. I want someone my own age”.

— Tower Hamlets PCT—the PCT identified a significant spend on unnecessary admissions to local Accident and Emergency departments. Analysis of focus groups and consumer data found that local residents trusted the opinion of hospital doctors more than local GPs. The PCT carried out a local education campaign outlining the appropriate use of local health services including GPs and pharmacists. Numbers of local residents presenting to A&E fell.

— Slough PCT—increased its early detection of diabetes by 164% by creating a tailored awareness campaign for local residential areas: Action Diabetes. Local diabetes patients, acting as health advocates, visited specific residential areas where populations likely to be at high risk of diabetes live. A mobile testing bus went to workplaces, shopping and leisure centres. The campaign also included a free health magazine, health information in different languages, celebrity support and local media coverage.

Should the committee wish to interview representatives of the campaign or the organisations we would be very happy to facilitate this.

Tim Kelsey  
Chair, Executive Board, Dr Foster Intelligence

January 2007
Evidence submitted by Ealing PCT PPI Forum (PPI 133)

If there is to be a REAL consultation on how LINks should be designed then different options must be offered. Included in these the Patient and Public Involvement Forum for Ealing PCT felt there were two essential proposals.

LINks should have access to all statutory health and/or social service provision plus services provided by private and/or voluntary contracts commissioned by statutory and social services. Without this overall access, monitoring and involvement, consultation cannot be maintained with any conviction.

Funding should come directly from the Department to the LINks. The idea that local councils should provide “support” and scrutiny committees should have any managerial function would not convince the public that LINks was truly independent.

Central funding would enable LINks to set up not only local but small Regional and National support services capable of providing general information and collating and consulting, for example on good practice throughout the country.

It is impossible to visualise local government “support officers” having this opportunity without which LINks would not be able to provide value for money and obtain the credit of both providers and users of health and social services everywhere.

We have already commented more fully elsewhere to the PPI Team at the Department of Health in respect of the Stronger Local Voice document, but believe that the two proposals from our Forum now emphasised, should be included in your own consultative procedure.

Patricia Seers
Chair, Ealing PCT Patient and Public Involvement Forum
11 January 2007

Evidence submitted by East of England Ambulance PPI Forum (PPI 124)

We are writing on behalf of the Forum members of what was previously covering the East Anglian Ambulance Trust area. We now form part of the larger Forum membership covering the new East of England Ambulance Trust.

We were represented at the All Party Parliamentary Group reception on the 30th October last and wish to add our comments to your Committee’s evidence on the inquiry into the future of patient and public involvement in the NHS.

1. Establishment of LINks

We are concerned after barely three years the government is proposing to abolish Forums and substitute LINks. It appears that the main contact will be Overview and Scrutiny Committees, which have a very wide remit covering health and social care.

Whilst this local group within the new Forum has good informal contacts with the three OSC’s of Norfolk, Suffolk and Cambridge it is felt that any new arrangement, indeed line of contact, will take some time to develop effectively. This at a time, when the rate of investment in the NHS is slowing, and further pressures will be put on Trusts to maintain quality services. This will need careful monitoring by a patient organisation.

2. Financing of LINks

The draft proposals to hand indicate that local government will fund the LINks with money provided centrally. This money, we understand will not be ring fenced. This local group is not satisfied that adequate funds will be available to:

(a) Resource the work of LINk members.
(b) Adequately support the costs of a support staff in the way FSO’s are funded at present.
(c) Make it increasingly difficult for any project work requiring even modest funds to be carried out. We assume that a competitive bidding process would be required for limited funds and this would take time. We accept that any proposal would require clear justification but in the light of recent experience feel that the process would be tortuous.

LINks would need to be transparently funded with members being aware of the sums available. Adequate resources should be made available for marketing and publicity, which has not been the case for the current PPI Forums.
3. **RELATIONSHIP WITH OSC’S AND TRUSTS**

It is essential that LINks as presently proposed should:
(a) Be seen to be autonomous.
(b) Not subservient to OSC’s but equal in their dealings with Trusts.

4. **POWERS & RESPONSIBILITIES**

Any Public & Patient group with statutory powers should:
(a) Fully represent all who make use of the NHS.
(b) Draw members from across the community by means of selection and co-option.
(c) Have full rights, within agreed protocols, for access to all areas and services provided by the NHS and associated organisations.
(d) Be part of the consultation process on the provision and alteration of NHS services.
(e) Within the regulations establishing such groups, be fully autonomous and independent of control by the Department of Health.

5. **STRUCTURE**

The new Public and Patient groups, be they LINks or any other arrangement, should be part of a regional structure, co-terminus with the current SHA’s and with a small national structure provided to ensure that co-operation and liaison on important national issues are covered.

6. **RIGHT OF APPEAL**

The new LINks or groups should have a clearly defined right of appeal to the Secretary of State.

7. **STABILITY OF ANY NEW STRUCTURE**

It is felt most emphatically that it would be better to delay any change in the present structure, to ensure, that any new structure is robust and has the confidence of the public, patients and the NHS.

**CONCLUSION**

Given the background and experience of the members of the Forum, we would welcome the opportunity to give verbal comment on our experience over the last three years and our hopes for patient and public involvement in the future of the NHS.

Whatever policy is finally implemented should be robust, effective and structured in such a way as to have the confidence and enthusiastic support of the community at large. The NHS would then be truly world beating.

*Jon Rapley*
Vice Chair, East of England Ambulance PPI Forum
*10 January 2007*

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**Evidence submitted by Epilepsy Action (PPI 36)**

Epilepsy Action is the UK’s leading epilepsy charity. Our aims are to improve the quality of life, represent and promote the interests of the 456,000 people living with epilepsy in the UK.

*In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?*

1. Epilepsy Action considers that wide public consultation should play a fundamental role in the decision-making process. Wider public consultation should take place in ongoing service planning, in the development and examination of new proposals and when decisions are being taken on general service delivery and major changes.
2. It has been widely acknowledged that there is a significant shortfall in the provision of epilepsy services in the UK. The Chief Medical Officer has confirmed that epilepsy has suffered historical neglect and lack of investment compared with other long-term conditions. As a result there is a serious treatment gap for people with epilepsy.

3. Epilepsy specialist nurses play a crucial role in supporting people with epilepsy. They enable many patients to manage their epilepsy effectively and to remain independent in the community. Guidelines have been produced in recent years which state the importance of having Epilepsy Specialist Nurses. These include the National Institute for Health and Clinical Excellence (NICE) and Scottish Intercollegiate Guidelines Network (SIGN).

4. NICE acknowledges the importance of the role of specialist nurses. In its epilepsy guideline, NICE says that epilepsy specialist nurses should be an integral part of the network of care of individuals with epilepsy. Their key roles are to support both epilepsy specialists and generalists, ensure access to community and multi-agency services, and provide information, training and support to the individual, families and carers.

5. Epilepsy Action is committed to supporting epilepsy specialist nurses. The Sapphire Nurse Scheme reflects Epilepsy Action’s commitment to improving health care services for people with epilepsy, working in partnership with funders and health care providers. A Sapphire Nurse is an epilepsy specialist nurse whose post was funded initially by Epilepsy Action. Epilepsy Action provides pump prime funding for a Sapphire Nurse post for either one year for a full-time post or two years for a part-time post.

6. Since the Sapphire Nurse Scheme began in 1995 Epilepsy Action has provided pump prime funding for 83 Sapphire Nurse posts, investing £2.5 million into the UK health service. Epilepsy Action never commits to pump prime fund a nurse post without assurance that the post will continue to be funded by the acute trust or primary care trust after the period of pump prime funding has ended.

7. In November 2004, a consensus group of expert clinical epileptologists and representatives of the epilepsy voluntary sector met to review various survey findings characterising the current state of epilepsy care and to compare against standards outlined in the (then) recently published NICE guideline on epilepsy.

8. The expert consensus was that current services fall well short of the standards set out by NICE in terms of waiting times for specialists and diagnostic tests, and research findings indicate that little is likely to change in the next four years. The expert consensus group called for a number of changes to be made to improve the shortage of neurologists and other epilepsy specialists.

9. In the short term the expert consensus calls for a national plan to increase the number of epilepsy specialist nurses from 140 to 600 across all epilepsy disciplines (adult, paediatric, learning difficulties.)

10. However, despite the acknowledgement of the consensus group that there should be a significant increase in the numbers of epilepsy specialist nurses, current epilepsy specialist nurse posts are under threat across the UK. At present, 10% of epilepsy specialist nursing posts are threatened with redundancy, working reduced hours and being reassigned to non-specialist duties, or epilepsy specialist nurses are leaving their posts and not being replaced.

11. Epilepsy Action considers that wider public consultation should take place in such circumstances where health trusts are considering cutting specialist services. This should take the form of consulting with patients, doctors, the general public and other relevant bodies, including the voluntary sector. Epilepsy Action believes that it is crucial that the people who are using these services are involved in the decision-making process and that consideration is given to the viewpoints of people who are benefiting from the service.

Michaela Miller
Campaigns & Policy Officer, Epilepsy Action
8 January 2007

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17 SIGN Guideline No. 70, Diagnosis and management of epilepsy in adults, Quick Reference Guide. April 2003.
18 To be confirmed.
Evidence submitted by Epsom and St Helier University NHS Trust PPI Forum and Sutton and Merton PCT PPI Forum (PPI 93)

A. BACKGROUND

Forum members from Epsom and St Helier University Hospitals NHS Trust and Sutton and Merton PCT PPI Fora have agreed on this response regarding the proposals in the DoH Document “A stronger local voice” to abolish Fora (and CPPIH) and replace them with Local Involvement Networks (LINks).

B. GENERAL CONCERNS

Before listing our specific concerns we wish to make some general observations. There is much talk, and presumably some intention, to provide a “Patient Led” NHS. However in the area served by our Trust/PCT (ie the London Boroughs of Merton and Sutton and a goodly slice of Surrey) there is great concern amongst the general public, patients and staff about the direction of future health care. We appear to have abandoned an exciting re-organisation (known hereabouts as “Better Healthcare Closer To Home”), the Trust CE has departed abruptly and both the Trust and PCT face massive financial deficits.

In response to this we are aware of three potentially conflicting “strategies”:

1. At the highest level we read of the Department proceeding with plans to focus on Regional Centres of excellence, in addition to reducing the number of A&E departments nationally.

2. At the Regional level we know London Region is processing a strategy which is rumoured to consider there are “too many” hospitals in (South West?) London (we also know the South Coast Region are contemplating “re-organisations”/closures?) across Surrey.

3. Locally the Trust is re-organising to both put its own house in order and respond to financial pressures. Thus it has re-aligned emergency and elective surgery, and is moving on to change Women’s & Children’s services. Further changes involve the introduction of cold meals and improving patients’ Length of Stay.

The point we want to make to the HoC Committee is that we do not see how Patients can directly influence any of these decisions? Of course when a change is considered a “significant change of service” (and this is undefined) we enter a period of (imperfect) public consultation. However the Committee will appreciate the patient and publics are only being asked to discuss what has already been determined and/or decided!

Empowerment (or a patient led NHS) needs to address this and also the welcome proposal that the HealthCare Commission Healthcheck evaluate exactly which changes have been made as a direct result of public/patient suggestions?

C. SPECIFIC POINTS

The purpose of LINks, as stated, is to create a larger group involving wider representation of patients/public/community. (eg MENCAP/Age Concern/Pensioner’s Forum). This larger group, the LINk, will be organised along Local Authority (LA) boundaries (where the LA has responsibility for social services): One LINk for each LA.

This implies that the Fora have been unsuccessful in fulfilling their remit to engage with the community, and to reach especially the disadvantaged and marginalised. In our experience, that same aspiration applies to the work of a plethora of public statutory and voluntary agencies. We have all made attempts to broaden involvement in this way, with disappointing results. This is not for lack of effort, so we wonder what is being built in to the LINks’ initiative to give it a better chance of success in this context. Why could the same resources not have been applied to the existing PPIF structures instead of the expense to be incurred in dismantling CIPPI/PPIFs and creating another forum to do similar work?

The proposal to establish LINks co-terminus with LAs, is going to leave hospital trusts in a very curious position. One of the PPIFs contributing to this response currently has a direct and sole responsibility to work alongside the Epsom & St Helier Hospital Trust as a clear independent voice for patients and the public who come from a number of neighbouring PCTs, (and some others further away whose GPs recognise the specialisms of the hospitals and what they offer their patients). The majority of patients, however, come from the Sutton & Merton PCT, or the Esher and East and Mid Surrey PCT localities. The existing two-way pull on the Trust will become greater, particularly, as the main existing acute hospital (St Helier) is at the northern end of a long narrow Trust area remote from its Surrey residents. The need will be, therefore, for the public in all the Trust area (ie both London and Surrey ends) to be represented by a body capable of putting forward coherent Trust-wide representations. This is preferable to three separate LINk bodies one of which, will be occupied with much wider responsibilities, including another major hospital Trust, thus reducing its focus on the E&StH Trust.
Already the Surrey end is under-represented in the Epsom and St Helier Forum and it has been exacerbated by the re-organisation of Surrey into one huge PCT. The current proposals do not appear to be designed to give the Surrey end a more balanced representation. If anything, it is likely to have a weaker (less-focused) voice to the detriment of the residents of the Trust’s Surrey end.

The assumption appears to be that this LINk would be properly funded (up to £150K) and organised (eg in our locality by a well staffed “Sutton CVS”), hopefully with a prominent and visible LOCAL presence.

However our discussion decided:

- the new larger group (LINk) might have more clout; but
- would be more difficult to organise;
- would have more diverse views; therefore
- more difficult to determine/agree priorities, prepare action plans etc.

One problem our existing Fora anticipate is: that if we are to be de-coupled from our existing organisational responsibilities(Trust & PCT), and the LINk is based on a (social services) Local Authority, this could lead to the creation of up to three (rival?) LINks (eg a Sutton LINk, a Merton LINk and a Surrey LINk). The Trust, which is retaining responsibility for Sutton AND Merton, might not appreciate having to deal with all this.

As a consequence of this de-coupling it appears the LINk is to focus on the health and social care needs of the community, and the range and quality of the “providers”. The present activities of inspection and visits will be removed. The intention is that in future this “inspection” work will be undertaken as part of the Health Commission Healthcheck. This is a waste of two and a half year’s work when the Epsom & St Helier Hospital Trust Forum has formed an excellent relationship with the Trust, and carried out several “visits” to specific units/departments of the hospital(s). Our members enjoy the visits and contacts with patients to discuss aspects of cleaning, catering and care. There will be a sense of “loss” which will influence members’ desire to continue. Even so current members have been dissatisfied and frustrated by the lack of time and resources to enable them to carry out this important “hands-on” monitoring aspect of their role. There is a danger that the new proposals will produce an even less effective and meaningful system and, not as is implied, a stronger one.

There is an existing (Section 11) responsibility for Trusts to involve and consult PPIF in the planning and development of health services and how they operate. The impression from the latest document is that the Commissioning of local health services (by a variety of bodies eg PCT and PbC) will be monitored by the LA Overview and Scrutiny Committee. The LINk’s work will be focused on monitoring the effectiveness of the delivery of these (commissioned) services, referring concerns (as now) to the OSC.

Each Forum currently wades through masses of paperwork and other material such as emails which CPPIH appears to produce quite regularly but not always in a focused fashion. This is often background information which requires sifting and analysing. The local Forum Support Officer has introduced a system of alerting us to relevant material without inundating us with it. However, it has taken time for this system to evolve and depend on the Officer understanding and appreciating our roles and responsibilities. The LINk will likewise be required to analyse and interpret a great deal of information—eg patient surveys, local experiences, and community priorities. This monitoring of “delivery” (by provider A) would seem at variance with the need to decouple from provider A. In any event cutting back on resources will result in the new body being unable to do its work actively.

Presumably the new PPI Resource Centre and Social Care Institute for Excellence (SCIE) may assist in research but clearly each LINk will need a properly funded research person, in addition to a person devoted to identifying relevant community groups and visiting them to publicise the LINk and establish the issues that need to be discussed. This is much more of a community development role and certainly not just an administrative function.

The emphasis on the OSC involvement with Commissioning implies the OSCs will be trained in this topic. LINk training on Commissioning, the financial arrangements of the NHS and the Resource Centre is also vital.

Our Fora have been actively involved in several far reaching public consultations and “Open Days”. It is unclear how future LINks might be active in this way?

Local Authorities are required to arrange the tendering process for the new “FSO” activity. We feel strongly that the people for whom this FSO function is to benefit, should be involved in the tendering process also. Are the present Forum/LINk members to be involved?

There appears to be no direction or guidance in place or in the pipeline regarding the practicalities of how the LINk will be convened, managed, function on a day to day (or periodic) basis. If the new FSO (equivalent) is to determine this, it is all the more vital that the PPIF/LINk members have a say in how this
is organised. At very least, those members of our Fora who have stayed the course, have acquired a great deal of working knowledge about the complex nature of the Health Service and the procedures and processes employed locally to ensure it functions adequately. It will be a massive waste of public resources if this experience is now jettisoned.

With a new (London) Strategic Health Authority, new PCT boundaries and responsibilities and new providers emerging one can see some logic in having a “new PPI”? However an alternative might be to maintain an element of continuity by using the contacts and experience of existing PPI structures and persons as the kernel of new activity?

The document concludes by mentioning a new National Network (how will this relate to the evolving PPI Forum network?) and the need for “users” (is this newspeak for patients?) to be more involved in regulation? Both topics need further explanation.

This review of the functioning of Fora need not have resulted in their execution. We have indicated several reasons for believing that PPI Fora have accumulated a great deal of relevant knowledge and skills and are a resource too valuable to discard.

What the reorganisation does provide is the opportunity to look at the multiplicity of patient and specialist representative groups before the PPIFs came into being. Our PCT had already launched its own PPI in common with any other PCTs and Trusts. Inevitably there has been lack of clarity regarding the roles of the different bodies and potential confusion about responsibilities and authority.

A very positive statement (on p 18) is that “commissioners will publish regular reports of WHAT THEY HAVE DONE DIFFERENTLY as a result of what they have heard (from LINk) and say WHY they might not have taken forward some (LINk) suggestions.

We look forward to seeing the first of these reports and noting how things have improved.

Jas Weir
Chair, Epsom & St Helier NHS Trust PPI Forum

and

Nick Pizey
Chair, Sutton and Merton PCT PPI Forum

10 January 2007

Evidence submitted by South East Essex PCT PPI Forums (PPI 136)

1. What is the purpose of patient and public involvement?

The members view is that their primary purpose is to be aware of the health needs of their local population, to communicate these needs to the relevant organisations, and to assist all organisations connected with the provision of local healthcare services to match those needs in a timely, affordable and practical fashion. This assistance will include advising these organisations on the steps needed to be taken to assist the local population to manage their own and their families heath and to “live healthily”. Members are expected to be aware of the needs of all groups including and not limited to ethnic minorities, young people, the elderly, hard to reach groups including commuters, a particular problem in south east Essex.

In detail:

— To provide help with the design of services and commissioning.
— Ensure that the right services are developed and result in the best outcomes for the local population.
— To capture experience of using services.
— To hold the local services to account.

2. What form of patient and public involvement is desirable, practical, and offers good value for money?

Members believe that the present model, that is the local patient and public involvement forums in southeast Essex fulfil these criteria. Members believe that their remit needs to be expanded to include social care. Members are not paid for their work. They are dedicated to the task of improving local health. They are effective. They have many years of valuable experience of the local area and service providers and their organisation works. The costs of running the forum is low and is confined to members' expenses, which are modest, the forum support organisation, space, and office equipment. We understand that the forum costs are approximately £30,000 pa Members do not need an expensive headquarters organisation to support them, just good locally provided support. It has taken about three years to reach this position. On the grounds, if it is not broken, don’t fix it; members believe that with some relatively minor changes, the current model can be made even more effective.
3. Why are existing systems for patient and public involvement being reformed after only three years?

Members consider that they have done a good job and are becoming more effective with the passage of time. Members do not understand why their forum is perceived to have failed and consequently are unable to answer the question with authority. To the members, it is change for change sake. Members are even more mystified why a change is being proposed when the replacement organisation has not been defined.

4. How should LINks be designed, including:

Remit and level of independence

The remit must include social services in a similar way to health services. Members get similar numbers of complaints about social service provision as they do about NHS service problems. The boundary between health services and social services strikes members as artificial, and not helpful to the local population. Otherwise the remit should be similar to that of the existing forum remit. Members believe that they should not have conflict of interests which in any way reduces their independence from local service providers (including charitable organisations) and local pressure groups including local politicians.

Membership and appointments

Members are not happy with the present arrangements for appointments. Members are aware of the long period of time taken by CPPIH to appoint new members and believe that a local mechanism has a lot to commend it. Ideally, forum members would like to see a local democratic process to recruit members and for forum members to be part of the selection process. We suggest that we should work with the local voluntary organisation to advertise, select and recruit. The evidence suggests that this process has worked well. The process of recruiting can be modified with experience gained.

Funding and support

Note forum includes LINks or similar title.

Each forum should budget its proposed costs, then hold its own budget and report on expenditure and achievement annually. The funding should cover: rental and operation of premises—a small office and meeting room, forum support (usually one person with limited arrangements for cover of holidays and illness), office equipment including Internet access, stationery, postage, telephones, lighting, heating and cleaning. Sharing premises with a local charity would make a lot of sense. The forum will also need capital for office equipment and running investigations.

The local authority seems the best organisation to provide this money. We believe that there could be problems with this arrangement, but alternatives seem potentially worse. We believe that the Department of Health would be unwilling to provide monies without an excessive amount of “red tape”.

We believe that it would be sensible to gain charitable status so that we would be able to raise money to support the work of the members. We envisage it would take time and effort to make this work satisfactorily and we would need pump priming to get going.

We believe that the Department of Health might be willing to pay for patient and health and social service surveys and this source of revenue could be developed with time.

Areas of focus

— The patient journey experiences.
— Experiences of social services.
— Assisting with establishing practice based commissioning.
— Reducing health inequalities.
— Determining local health issues and recommending corrective action.
— Capturing and analysing the patient experience and reviewing this with the relevant organisations and follow up where necessary.

Statutory powers

— Similar to those of the patient forums.
— Sight of contracts for practice based commissioning (subject to non-disclosure agreements).
Relations with local health Trusts

— Critical friend.
— Constructive.
— Access to Directors, Chief Executives and Chairmen.
— Work in partnership where possible.

National co-ordination

— Minimal—restrict to codes of conduct and functional guidance. The emphasis is local at all times.
— Informal links to other Forums.

5. How should LINks relate to and avoid overlap with:

Local Authority structures including Overview and Scrutiny Committees (OSCs)

As now. Work together. Forums pass issues to the OSCs. OSCs get evidence from forums. Discuss common issues. Forums second members to OSCs with non voting rights.

Foundation Trust Boards and Members Councils

Formally via the PCT and informal contacts.

Inspectorates including the Healthcare Commission

Pass reports on local experiences to the Healthcare Commission. Meet with the Healthcare commission when the commission requests a meeting. Have a formal agenda and respond to requests for information in a reasonable timeframe.
— Regular contact with the commission to understand commission objectives.
— Report on the commission to the Department of Health.

Formal and Informal complaints procedures

We believe that the existing mechanisms are basically sound. Members should pass problems to the appropriate PALS (as now) and refer complaints to ICAS (as now). We are aware of public concern about complaints procedures, but believe that with the current changes in the NHS, that all trusts will become more responsive to complaints and for our members to get in the way of this change will be unhelpful. Our role should be to provide an evidence based big picture and not be another complaints handler. Trusts will need to get their acts in order to maintain income. We believe that this will result in the best outcome for all (patients and care providers). We would like to see all trusts welcoming complaints as a form of low cost marketing information and not as a cross they have to bear.

6. Conclusion

Patient Forums are not perfect, but they are not beyond repair. To replace them with another organisation when they have just got going is unhelpful to patients’ interests.

Members agree that social care must be added to the responsibilities of the forums. Members are already involved in this area and can absorb the additional work.

Members believe that local is best and that national organisations are unhelpful.

Members understand local issues. Use them where they can be most effective.

Members believe that wider consultation under Section 11 would be helpful and this should be performed now.

Harry Chandler
South East Essex PCT PPI Forum

January 2007
Evidence submitted by West Essex PPI Forum (PPI 29)

PREAMBLE

1. The draft Local Government and Health Bill includes provision for the abolition of Patient and Public Involvement Forums on the basis, it seems, that Forums have not achieved the full scope of local interaction envisaged, and that when there are relatively few members there is a risk that personal agenda may be pursued.

PROBLEMS OF DICHOTOMY

2. As a Forum we have been aware of the difficulties that arise at the interface between Health and Social Care, with a division of responsibility and accountability which may often be to the detriment of the patient or client. We would therefore support measures to promote a seamless spectrum of care, particularly for the aged. It is apparent that this is the motive behind the creation of LINks, which are to be based on the administrative areas of Social Services, which are effectively co-terminous with County Councils.

The “devil”, however, “is in the detail” and there are features in the draft Bill which we believe not only to be unnecessary but actually to be counterproductive.

PROPOSAL TO ABOLISH PPI FORUMS

3. We firmly believe that the proposal to disband and abolish PPI Forums is absolutely in the category of unnecessary and counterproductive measures. The preferred option is to retain the new Forums with their existing statutory powers and responsibilities, revise their terms of reference and incorporate these Forums as integral to the core of the larger LINks.

BACKGROUND

4. PPI Forums were formed after the earlier (and controversial) decision to abolish Community Health Councils. The change over has been quite difficult in some places, except where there was already in place an effective User Group. In Epping Forest this was the case, but our first Forum Support Organization went bankrupt and had to be replaced at short notice by a body with no health service experience, which in turn had also to be replaced. It took a good two years for our Forum to get “up to speed” and our experience was by no means unique.

5. Important Differences from CHC’s were the removal of responsibility for individual patient complaints and alignment with an individual Trust. The latter change, associated with the Purchaser/Provider split caused some confusion and difficulty in situations where both PCT and Provider Forums had a legitimate interest. Cross communication and co-operation were essential, but magnified the complexity and time involvement for Forum members. As a result there has been considerable turn-over in membership of many forums, but with Forum function reaching a steady state, a nucleus of very dedicated individuals, quite often with some relevant health related expertise, has emerged.

RECENT DEVELOPMENTS AND CONSEQUENCES

6. Further local upheaval has been brought about by the amalgamation of Primary Care Trusts (13 down to five in Essex), the “scrambling” of Forum Support Organizations, and now the fore-shadowed abolition of Forums with the formation of LINks (with an elongating time scale now likely to extend to 2008). We have already seen significant “haemorrhage” of experienced Forum members, who, in spite of official protestations, feel undervalued and stifled. This means the loss of useful personal and local knowledge built up by the dedication of Forum members.

This “haemorrhage” is likely to become a flood if confidence is not restored.

SUMMARY AND RECOMMENDATIONS

7. The West Essex PPI Forum, together with that of our local acute Trust (Princess Alexandra Hospital), believes that the best way to achieve the increased representation expected of LINks would be to retain the presently reduced number of Forums as the nucleus of LINks, with their statutory powers intact, but with revision of the terms of reference to remove the overlap of activity.

8. The locality focus of the existing Forums has made a real difference to health care. We do not see a problem with the creation of Foundation Trusts as we believe there is a need for patient and public involvement from the Purchaser/Commissioning aspect to have “arms length” inspection and monitoring powers linked with those of the Governing Body.
9. We understand that the Government has already indicated a willingness to consider the retention of monitoring and inspection rights, but only for a core group, properly vetted and trained. We would suggest that this could most easily be achieved by retaining the existing Forum structure as a basis. This would go a long way to alleviate concerns about the loss of vitally important “local input” into health care planning and provision.

10. We hope that the Select Committee will give this serious consideration before the legislation is “set in stone”, and that the members appreciate that an early pronouncement could bolster morale amongst the voluntary supporters of the health service, morale which presently is ebbing steadily.

West Essex PPI Forum

January 2007

Evidence submitted by the Family Planning Association (PPI 82)

Further to the announcement that the Health Select Committee is to conduct an inquiry into patient and public involvement in the NHS and knowing the committee’s interest regarding sexual health, I am writing to highlight some issues of concern to fpa about the impact of public involvement on sexual health services.

fpa welcomes opportunities for the views of patients and members of the public to be taken into account during the development of health services and for people to make decisions about the care they receive. For example, ensuring access to information and the ability to make informed choices are fundamental to enabling women to use contraceptive methods safely and effectively.20

In addition, we know that taking the views and needs of all service users into account can encourage some people to use services more frequently, particularly those in harder to reach groups. There is evidence that services can actively discourage the involvement of boys and young men, through their publicity, their image in the community, the attitudes of staff or even their waiting area. Therefore, taking the views of people likely to use the service into account is a vital way of improving their access.21

However, fpa is concerned that an over-emphasis on the need for there to be strong patient calls in favour of services may lead to some services being neglected. Sexual health services, by their nature, do not lend themselves to concerted local support campaigns. The stigma that is still attached to sexually transmitted infections and to abortion mean that few people, even those who use the services, would be willing to campaign in favour of service provision.

There is already evidence that funding for sexual health and contraceptive services is being cut due to NHS funding pressures and there is a risk that already stretched trusts could be tempted to focus investment on those services for which there is vocal support. This would be detrimental to all sexual health services, including genitourinary medicine clinics, community contraceptive services and abortion services.

fpa is keen for people to be involved in decisions about their care and about health services. However, it is important that this does not happen at the expense of the development of vital but low profile services.

We would be very pleased to come and talk to your committee if you would find that helpful.

Anne Weyman OBE
Chief Executive
Family Planning Association

9 January 2007

Evidence submitted by Gateshead Hospitals PPI Forum (PPI 2)

1. What is the purpose of Patient and Public Involvement?

To ensure that delivery of health services meets local needs & desires and is not solely subject to national targets and directives.


2. **What form of PPI is desirable, practical and offers good value for money?**

A system which allows local people to be involved in:

- Determining local priorities.
- Mapping existing provision and identifying gaps.
  Designing the service specification—including methods & locations for service delivery, as well as quality levels and monitoring.
- Includes significant lay involvement in the actual monitoring of the services.

This obviously requires a fairly small group of people with knowledge of the local health economy, supported by paid staff, who can interact with a wide range of people and bodies.

Value for money is a relative judgement. If the government believes—as it claims—that local people are best placed to determine what health and social care needs exist, then it has to pay a reasonable sum to ensure involvement is effective. This is surely better value than the amounts which are spent on external consultants whose reports rarely fit into local needs.

Expenditure on supporting the Commission for Patient & Public Involvement and PPI Forums has been significantly reduced in the last year and is further reducing in 2007. This is significantly weakening the resolve and capability of PPI Forum members.

3. **Why are existing systems for PPI being reformed after only three years?**

   **No idea!!**

   There is considerable evidence that PPI Forums were beginning to make an impact locally, regionally and nationally. If there are parts of the country where PPI is not as effective as it is elsewhere the effort should have been put into improving these areas—not destroying the rest of the system.

   In addition to the actual impact on health service provision PPI Forums are also increasing their contacts with local groups, effectively creating the networks that LINks are designed for.

   CPPIH and Forums were destabilised from the beginning with the Dept. of Health announcing a Review of Arms Length Bodies just after Forums were formed. Almost as soon as this announcement was made there were rumours that CPPIH would be abolished and Forums were facing an uncertain future.

   PPI should have been given at least five years to mature and make the desired impact. The NHS is a very complex structure and the vast majority of people have no idea of the difference between primary and secondary care. They are not even concerned about this distinction and, as far as they are concerned, they deal with the NHS as a single body. If significant changes about the way the NHS works are being introduced—as is the case—and more emphasis is being put on “local” services, it becomes obvious that patient and public input needs to come from people with a reasonable understanding of the implications. In many cases this means PPI Forum members who have spent 3 years building up knowledge.

4. **How should LINks be designed?**

   **Remit and level of independence:**
   - To identify local priorities and concerns;
   - To be totally independent of both the NHS and local authorities, so that the public perception is that LINks are there to represent them and not the vested interests of public bodies or politicians;
   - The remit and responsibilities should be made clear from the outset because they will in part determine the structure and organisation of LINks and affect how membership is determined.

   **Membership and appointments:**
   - Membership should be open to anyone who has knowledge of, or an interest in, local health service delivery;
   - However, members should have a wide perspective on health issues and not be allowed to promote a single group or individual condition;
   - Decision making should be by consensus and anyone with a potential conflict of interest should declare it (eg someone who represents a group who are or will be applying for contracts to supply services to the NHS or local authority OR represents a group which campaigns for a particular condition);
   - People falling into this category should bring information and expertise to the discussion but not take part in the actual decision making;
   - Each LINk should decide how it wants to operate and this will inform how members are appointed;
The exception to this is, as is currently the case with PPI, senior officials and managers of NHS Trusts and local authorities, as well as local politicians involved in Health and Social services scrutiny.

Funding and support:
- Funding should be guaranteed and available for a minimum of five years (subject to performance);
- Funding should be at “full cost recovery” and include increases for inflation and salary progression;
- It should include sums for publicity and, as necessary, employing specialist consultants;
- It should include a reasonable sum for training LINks members and reflect the fact that there will be considerable turnover—so training will be ongoing;
- Support should reflect the fact that LINks members will be volunteers with limited time and the support cannot be purely administrative. It has to include research and an understanding of policy and strategy.

Areas of focus:
- Geographically, primarily within a local authority area but, because the NHS makes many decisions at a sub-regional, regional and national level LINks must be able to interact and do the same;
- Specialist NHS Trusts such as mental health, ambulance and rare conditions need to be responsive to all of the associated LINks—possibly through the Commissioning process.
- The focus in terms of services should reflect the priorities and concerns of local people.

5. Statutory Powers
- It is crucial that LINks have the ability to require information and monitor/inspect as part of the assessment of the actual delivery of services;
- There is no point in spending months—even years—involve people in the design of a service and then stopping them seeing how well it is being delivered;
- This becomes even more important when dealing with services commissioned from the independent sector. The public is paying for these services and expects to be able to make the same demands on the private sector as it does the public sector.
- “Commercial confidentiality” has nothing to do with the quality of service delivery and independent/private sector providers should be subject to the same accountability as the NHS or local authority;
- Nor should LINks only be allowed to exercise these powers under the direction of another body (eg the Healthcare Commission). LINks need to be able exercise these powers as they deem fit to carry out their own duties, not someone else’s.

6. Relations with Local Health Trusts
- It makes perfect sense for LINks to work constructively with the NHS (and local authorities). LINks need to understand the pressures placed on these bodies by central government and this can only be achieved by open and honest discussion;
- However, where LINks identify a problem, they should be free to highlight it and seek corrective action from the NHS or local authority. In the absence of acceptable remedial action LINks need to be able to raise their concerns at another level;
- As indicated above, there are NHS Trusts which cover a number of local authority areas and their accountability should be to all the LINK areas they serve.

7. National Co-ordination
- LINks need to be able to identify best practice from around the country AND make enquiries to see if a problem they have identified is purely local or, in fact, has arisen in a number of areas;
- There is also the possibility that the issues identified by LINks are the result of a national policy and the only way they can be resolved is if that policy is amended or scrapped;
- In the absence of a national “route” for LINks this is unlikely to happen.
8. **How Should LINks Relate to and Overlap With**

Local Authority structures including Overview and Scrutiny Committees:

— There are different powers and concerns for these bodies so they each have to recognise these differences and try to establish suitable relationships;

— Both LINks and OSCs will have work programmes and, at the very least, they should share these with each other;

— In doing this they would know whether an issue which has been brought to the attention of a member of the LINk or OSC is already being considered and whether or not there is scope for joint working;

— Unfortunately you cannot force LINks and OSCs to work co-operatively, even where this would be sensible. There are issues of capacity (OSCs have work passed to them by local Cabinets, as well as having a statutory duty to look at particular LA policies) and they may not be able to take on extra work. Equally, LINks will have competing demands on their time and face the same problem;

— This reinforces the need for a national route for LINks—if OSC declines to investigate a topic the LINk thinks is appropriate for the OSC the LINk needs an alternative way of tackling it.

Foundation Trust Boards and Member Councils:

— Until such time as a Foundation Trust Board can demonstrate that it uses its membership fully and effectively to identify local priorities and needs it should be required to work constructively with LINks;

— Even when Foundation members are active and fully engaged the LINk could continue to provide an additional source of information to the Trust;

— Foundation governors have a different remit from LINks and, in fact, have very limited “powers” when compared with the current PPI Forums. Exchanging views and information—in the same way LINKs and OSC should—would encourage constructive engagement with the Trust as a whole;

— Gateshead Health NHS Foundation Trust is a good example of what can be achieved where the PPI Forum has the right to appoint a Governor and this individual is able to take issues back and forward between the Governors and PPI Forum and identify the best route to investigate and resolve problems.

Inspectorates including the Healthcare Commission:

— Information from inspectorates can be very useful to LINks;

— Equally, the views of LINks could act as a prompt for inspectorates to investigate certain aspects of a Trust’s service delivery in more detail;

— However, LINks should not, and cannot, be a tool of inspectorates. Where a LINk has the desire and capacity to help a particular inspectorate it should do so but no inspectorate should be able to force a LINk to do a particular piece of work.

Formal and informal complaints procedures:

— The volume of complaints, looking at social services and primary and secondary NHS delivery, would overwhelm a LINk;

— The NHS and local authorities have their own complaints systems (both formal and informal) and the role of the LINk should be to ensure these are widely publicised, easy to use and that the public can have faith in them;

— LINks should, however, have access to details of the types and numbers of complaints because they are an indicator of how the public perceives the service under consideration.

10. **In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?**

In the absence of details about the “strengthening” of Section 11 it is difficult to comment.

— The current requirement is that NHS Trusts consult over the introduction of new services or where there is “a proposal to make a significant variation” to an existing service. There should be a single national definition of the term “significant” and it should be agreed by patients as well as the NHS;
It is important to ensure that Section 11 includes restructuring and reorganisation of the NHS. At the moment the NHS does not have to consult over these because they about “management” not service delivery. This is patent nonsense since changes to management structures have a direct bearing on an organisation’s ability to deliver services;

For example the recent PCT reconfiguration exercise. Some PCTs in the North East were merged but others, because of public opinion, were retained. However, those which did not merge were forced to make an equivalent management saving and have undergone a de facto merger whilst retaining their original names. The board and management structures, commissioning arrangements and HR functions have all changed;

Consultation should take place over a reasonable period of time and take many forms to ensure that the widest possible audience is reached;

Once consultation is concluded and decisions are made details of public comment obtained during the exercise should be released so that it can be shown that the NHS organisation took the comment into account;

This should not be the Trust’s own interpretation of comments received but the actual comments.

Gateshead Hospital PPI Forum
14 December 2006

Evidence submitted by General Medical Council (PPI 147)

The Role of the General Medical Council (GMC)

1. The GMC welcomes the opportunity to assist the Health Select Committee in its inquiry into patient and public involvement in the NHS. This submission provides information on the following:
   (a) Our statutory role as the regulator for medical practitioners registered in the United Kingdom.
   (b) Information on involvement of patients and the public in our work.
   (c) Information on how we further plan to engage with patients and the public.

2. The GMC’s role in the regulation of doctors is defined in our statutory and charitable purposes: to protect, promote and maintain the health and safety of the public by ensuring proper standards in the practice of medicine. The law gives us four main functions under the Medical Act 1983.
   (a) Keeping up-to-date registers of qualified doctors.
   (b) Fostering good medical practice.
   (c) Promoting high standards of medical education.
   (d) Dealing firmly and fairly with doctors whose fitness to practise is in doubt.

3. Although we are not in a position to respond to all the issues raised in the Committee’s terms of reference, this submission provides background to the key elements of our own PPI activities and the principles which underpin our work in this area. The challenge we face in involving patients and the public in the work of a regulatory body is somewhat different to that faced by a NHS body or commissioner of healthcare services who have a need to involve front line service users. However, the involvement of patients and the public in the development of regulation is critical if regulation is to be both effective, proportional and retain the confidence of the public. The lessons we have learnt through our experiences in involving patients and the public may be of interest to the Committee and with this in mind we have made a number of general comments about the issues raised by the Inquiry.

Our Experiences of Patient and Public Involvement

4. Effective engagement leads to better informed and therefore better designed policies and outcomes. However, good policies alone are not enough. For systems of healthcare and the regulation of healthcare professionals to be effective, they must command the confidence and support of patients and the public. Although surveys show that confidence in medical regulation remains high, only by engaging effectively with the public and demonstrating transparency and accountability can confidence be maintained in the longer term.22

5. Over recent years we have been striving to increase the level of patient and public engagement throughout our work. These initiatives have been wide ranging and offer opportunities for citizens, across the four nations of the UK, to input to our work. We have sought to take an innovative and proactive

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22 A recent research study undertaken by GfK NOP found that 76% of respondents were confident in the regulatory system.
approach, recognising that PPI is relatively new in the field of healthcare regulation. Some of the examples of our work in this area are described below. Annex A also provides further examples of our activities during 2006.

**Governance structures**

6. In our recent response to the Department of Health’s consultation on the future of healthcare professional regulation we proposed a package of reforms which we believe, if implemented, would help to deliver improved patient safety and can command confidence in medical regulation. At the heart of these proposals are changes in the governance of the GMC. We have argued that for the GMC to command the confidence and support of all interest groups, it is critical that not only must we remain independent from the government as the dominant provider of healthcare, but also be independent of dominance by any single group. To this end we have proposed changing the composition of our Council, removing the current medical majority and having an equal representation of lay and professional members. Membership of the new Council would consist of representatives from all our key interest groups. Our response to the Department of Health’s consultation also confirms our long standing belief that confidence in the GMC, and medical regulation as a whole, would be enhanced if we were to be accountable to Parliament.

**Fitness to practise**

7. We have, over recent years, enhanced lay input and decision making into our disciplinary proceedings. No fitness to practise decision is made without lay involvement. In those cases that culminate in a hearing, the fitness to practise panel will normally comprise three to five panellists. In addition to the chairman, who may be medical or non-medical, there must be at least one medical and one non-medical panellist on each panel.

**Citizens’ jury**

8. In November 2005, we held a Citizens’ Jury to consider a range of standards and ethics issues relevant to children and young people. This was the first such use of this approach by a UK health or social care regulator. The Jury, comprising 15 individuals from a cross-section of society, met for four days in London and took “evidence” from a range of “witnesses”, engaging with children’s charities, the police, lawyers, social workers, nurses, doctors, child protection experts and children themselves. The Jury provided valuable insight into how the various competing priorities, such as child protection and confidentiality, should be assessed. The Jury’s report, available at http://www.gmc-uk.org/guidance/Jury—Report—19—Jan—2006.pdf, has been used in the development of our guidance on treatment for children. Taking this work forward, we have now issued a consultation on the draft guidance.

**Development of draft guidance on children and young people**

9. In November 2006 we launched a consultation on new draft guidance for doctors about their role and responsibilities towards children and young people. We are keen to ensure that the consultation process is accessible to all, in particular children and young people. As such we have developed a website designed specially for children who wish to take part (www.gmc-uk.org/children). In addition to this, in partnership with the Teenage Cancer Trust and Rainbow Trust Children’s Charity, we have launched a poster competition asking under 18s to submit a design which will be used for the front cover of the new guidance booklet. It is hoped that this consultation will successfully capture the opinions of all those involved in the treatment of children, including young people themselves.

**Consultation on good medical practice**

10. The GMC has undertaken a wide-ranging and innovative two year consultation as part of the review of Good Medical Practice, our core guidance to doctors which sets out the principles and values upon which good practice is founded. The consultation process included research on public attitudes, a large scale written consultation and a series of open public meetings. These meetings took place across the UK and used a series of fictional scenarios to help us investigate and assess public opinion. The resulting guidance, the changes to which include an emphasis on the importance of the doctor-patient partnership, has been well received. A copy of the guidance can be found at http://www.gmc-uk.org/guidance/good—medical—practice.

11. To raise awareness of the new edition of the guidance we also launched a national poster campaign. The aim of this campaign is to encourage employers and GP practices to display the posters in their waiting rooms and public areas so that the public can be informed about doctors’ commitment to the principles of good practice in a relevant and accessible way. It will also highlight to doctors that the guidance has been updated and that they need to be aware of the professional obligations contained in it.
Development of the patient and public reference group

12. In 1999 we established our Patient and Public Reference Group which compromises representatives from patient and consumer organisations. The Group provides us with input from a patient perspective on the development of our policies. In 2006 we set out to add to the membership of the Group the voices of individual members of the public. The recruitment was open to all members of the public and was designed to encourage applications from those who had not previously been involved in healthcare or regulation. Annex B includes a description of the recruitment specification used as part of this process.

13. As a UK wide regulator, the GMC is committed to ensuring that we engage with patients and the public in all four countries of the United Kingdom. An example of this commitment is the development of country-specific patient leaflets and complaints forms to ensure that information provided to patients and their representatives take account of differing structures and complaints processes in the NHS across the UK.

Surveys

14. Since 2005 we have commissioned regular surveys designed to ascertain and understand public attitudes towards a range of issues facing the GMC and regulation. The results of these surveys have been fed into our policy development to help ensure that medical regulation meets the needs of society.

Joint health and social care regulators information leaflet

15. We recognise the importance of the patient and publics having access to clear and reliable information. Working with the 12 partner organisations, a public information leaflet has been developed and published. The leaflet, which was developed with the assistance of PPI Forum members, aims to provide the patient and publics with an easy to read guide to the work of health and social care regulators, how this impacts upon the patient’s experience and importantly how to contact the appropriate organisation. A copy of the leaflet, which is also available in 12 languages, can be found at http://www.gmc-uk.org/publications/regulator.

Readers’ panel

16. We have recently established a reader’s panel to work with us on improving the way in which we communicate with patients and the public. The role of the Panel, which is drawn from a public recruitment exercise, is to give feedback on our communications so we can ensure that the information we are providing is accessible and easy to understand.

Future Patient and Public Involvement Developments

17. The work we have undertaken in recent years has significantly increased the patient and public input in the development of medical regulation. Going forward we are eager to build upon this progress. As part of this we are currently exploring the establishment of a Patient Panel, drawing upon the experiences of others such as Ofcom, National Institute of Clinical Excellence and Financial Services Authority. In developing our plans for such a scheme we are keen to investigate how local networks such as PPIFs as they currently are, and LINks in the future, might be involved, further assisting in bridging the national and local divide.

18. Mechanisms for improving the connections between organisations such as the GMC and patients and the public are very welcome and we look forward to the opportunity to work closely with the evolving system of local patient and public networks as it develops.

Hugh Simpson
General Medical Council

January 2007

Evidence submitted by Hammersmith and Fulham Service User Network (PPI 68)

The Hammersmith and Fulham Service User Network aims to support people who use mental health services to get involved in influencing and improving the services they use. The project is funded by the Hammersmith & Fulham Primary Care Trust, and is based in Hammersmith and Fulham Mind.

The responses in this memorandum correspond directly to the points raised in the request.
1. What is the purpose of patient and public involvement?

1.1 The purpose of PPI is for service providers and commissioners to improve health services for patient and publics, based on the experiences of those who have used them. Public and Patient Involvement should enable service users, service providers and commissioners to communicate “first-hand” in order to achieve this aim.

2. What form of patient and public involvement is desirable, practical and offers good value for money?

2.1 Independently facilitated local involvement networks, linked to local NHS services would provide effective local involvement. These networks should be funded and coordinated through a national centre capable of supporting the networks to work together in developing, promoting and sharing effective local policies and practices at a national level.

3. Why are existing systems for patient and public involvement being reformed after only three years?

3.1 The experience of involvement for patients, public and providers is an inconsistent one; dependent on not just which Trust is concerned, but also which particular directorate or service. This is partly due to the very recent development and evolution of involvement where Trusts, directorates and services are learning as they go along. However this inconsistency is also heavily influenced by the attitudes, practices and policies of those Trusts, directorates and services. How patients and public are involved, how they are supported to be involved, and how their input is acted on varies greatly from service to service, even within a single Trust, leaving those involved often feeling unsupported and undervalued. This results in many potential contributors becoming disillusioned and unwilling to engage with the process. This results in the Trusts not receiving the quality of involvement, and therefore the improvement of services that they could achieve. This is not helped by the reliance of existing projects on local Trusts for funding and support; as the involvement can become partisan, or can get caught up in political and financial debate rather than concentrating on working as a critical friend for the benefit of the services. Greater independence at a local level and greater communication between projects at a national level would strengthen the projects’ abilities to engage and involve patients and public, as would more consistent policies and practices around support for involvement.

4. How should LINks be designed?, including:

4.1 Membership and appointments

4.1.1 Membership should be open to anyone who uses, or would potentially use NHS services in a local area.

4.1.2 There should be annual elections of members to committee roles, with at least two co-chairs for mutual support and continuity of service.

4.2 Funding and Support

4.2.1 LINks should be funded by the NHS through a national coordination centre. (See 4.5).

4.2.2 Local LINks facilitators should be employed to support patient and publics to get involved, and to support services to involve patient and publics. This includes advising local trusts of best practice based on examples shared nationally as well as ensuring more consistent support for patients and public (training, disability support, expenses and remuneration for their involvement).

4.3 Areas of focus

4.3.1 These should include existing points such as environment, cleanliness and food, as well as staff attitudes and capacity.

4.4 Relations with local health Trusts

4.4.1 LINks should be independent to Trusts at a local level to enable service users to act as a critical friend. This could take place through commissioning facilitation services to voluntary sector organisations or local Trusts. However, funding should not be set through local Trusts (see 4.5). LINks should also work with local groups and forums, as well as regional and national organisations to share good policies and practices.
4.5 National Coordination

4.5.1 Although operating at local level and funded by the NHS, commissioning should take place through a national coordination centre such as the new PPI Resource Centre. This will ensure that networks will truly be able to work independently with their local services without fear of financial reprisal, or the work of the network being disrupted due to local funding arrangements. The Centre should also facilitate communication and joint working, wherever appropriate between LINks at local, regional and national levels in the interests of sharing good policies and practices.

5. **How should LINks relate to and avoid overlap with**

5.1 Foundation Trust boards and Members Councils?

5.1.1 Members Councils and Trust boards should include LINks representatives, and should be accountable to LINks.

5.2 Inspectorates including the Healthcare Commission

5.2.1 Relations should be facilitated through a national coordination centre.

5.3 Formal and Informal complaints procedures

5.3.1 LINks should work with local PALS and ICAS, as well as Trust boards and Members Councils to ensure that complaints are investigated and appropriate actions taken.

6. **In what circumstances should wider public consultation be carried out and what form should this take?**

6.1 The wider public should be consulted about major changes to services and annual evaluations of services. This could be facilitated through LINks, providing that local networks are given advance notice of the work schedule.

Hammersmith and Fulham Service Users Network

*January 2007*

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**Evidence submitted by Hampshire County Council Health Overview and Scrutiny Committee (PPI 48)**

**What is the purpose of patient and public involvement**

1. We consider that the purpose of effective Patient and Public Involvement is to provide a route through which those making decisions about services are required to test and shape proposals in a way that takes account of the views of those actually using and funding services. There are a wide variety of institutional, professional and bureaucratic interests that are able to influence this decision making- this can lead to a situation where decisions about service delivery can be taken without account of its impact on those using services. Patient and Public Involvement, if effectively delivered can balance this influence and enhance accountability to patients and the public.

**What form of P&PI is desirable, practical and offers value for money**

2. Patient and Public Involvement must be understood and influential in the context of the system in which it operates. Public services such as health and social care are immensely complex and this is likely to increase given the programme of policy reforms that are now starting to emerge. It is essential that there is flexibility to tailor Patient and Public Involvement activity around local circumstances and the issue to be addressed. A prescriptive, “one size fits all” approach is will not work. Equally effective Patient and Public Involvement needs to work alongside, and not duplicate existing systems. It therefore needs to be distinctive in the work that it does. We have not yet been able to ascertain how LINks will meet these requirements.

3. Current proposals for LINks do not recognise the infrastructure already in place to allow for engagement with communities and support the accountability of public services, including representation by democratically elected members, LSPs and LAAs. The LINks need to complement the infrastructure in place to support these arrangements and not duplicate functions that are already embedded in, and working on behalf of, local communities. In this sense it is difficult to see how LINks will be different from other existing forms of engagement, particularly taking account of the changes set out in “Strong and Prosperous Communities”, which will strengthen the existing overview and scrutiny function of Local Government and provide a route for challenging issues of concern to communities through the “community call for action”.
Why are existing patient and systems being reformed after only three years

4. Despite the initial efforts to bring the new system to life there has been little or no practical support with the delivery of the Patient and Public Involvement remit at front line level. Problems with FSOs have seen some go into liquidation and others simply not cope with the level of input required. Other FSOs have worked well. Funding for the FSO contracts limited what could be offered and failed to take account of the skills it takes to secure meaningful feedback from different communities and process this to provide objective information or evidence for action. Patient and Public Involvement Forums have been continually frustrated by not having the resource to undertake this type of work.

How LINks should be designed to relate to and avoid overlap with existing local structures including:

Remit and level of Independence

5. Developing the point above we would ask that there is absolute clarity about the distinctive role that the LINk could bring to building effective community engagement and involvement across health and social care. They also need to be able to work across patient pathways that do not map easily with their geographic area. Hampshire for example is a large and diverse county. Some services, such as ambulances, now run across both Hampshire and Thames Valley whilst others are focused on practice based commissioning areas or district boundaries. LINks have to be able to respond to these very different models of care provision.

6. If different groups with competing interests are part of a LINk, how can they give an independent view of an issue. How can the LINk be held to account if it fails to fairly reflect the perspective of the community that it is supposed to serve because of conflicts of interest in its membership.

Membership and Appointments

7. Recruitment to these new bodies will inevitably be based on the perceived influence that the LINk can exert in the planning and delivery of local services. The way in which some Patient Forum members have been treated over the past 18 months has devalued and marginalised their role. CPPIH has generated a bureaucracy that militates against Forums active and timely engagement to shape services that are important to local people. It will take time to address these perceptions.

8. Equally there needs to be clarity about how LINks draw their views together and what perspective will shape these views. The old CHCs were required to take account of the “public interest” in coming to a view, HOSCs have to consider the impact of any proposals on the population affected, locally elected members can represent the views of their individual constituencies (and are directly answerable through the democratic process), the NHS has to take account of the views of current and future service users. Voluntary sector, independent and professional organisations are able to reflect other interests and views. LINks must be able to add value by drawing together views that otherwise it would not be possible to access.

Funding and Support

9. There has been significant variability in the hosting arrangements for the Patients Forums and a number of concerns that funding has not been available to support the activities of individual Forums in discharging their statutory duties. If public funding is to be properly monitored and controlled we would suggest that there is greater clarity about what it is that LINks are expected to deliver and flexibility in the options open to Local Authorities in ensuring that this is supported appropriately. Local circumstances vary widely, and it should be open to local discretion to determine the best way to support the delivery of this function. Rather than talking about model contracts that replicate previous arrangements it may be more helpful to set out a range of quality requirements that will be expected of any support provided to deliver the role of the LINk.

Areas of Focus

10. HOSCs already provide a mechanism through which local services can be held to account and are increasingly influential in the areas in which they operate. They are separate from the executive/service provision arm of local government and the NHS. Our view is that this function has considerably strengthened both decision making processes and the way in which democratically elected representatives can influence the way in which services are delivered to our populations. LINks need to complement and not duplicate this function and we have expressed considerable disquiet at proposals that seem to confuse our respective roles.

11. If their role is to be one of gathering additional information and experiences it needs to be equally clear what added value this brings given the fact they will not be the only route through which the service commissioners, HOSCs and others access the views of people affected by a particularly proposals. It would not be helpful if the introduction of the LINks undermined local arrangements around community engagement that are currently working well.
12. As currently proposed we believe that LINk will confuse, rather than compliment existing engagement mechanisms and those proposed through “Strong and Prosperous Communities”.

Cllr Dr Raymond J Ellis  
Chairman, Hampshire CC Health Overview and Scrutiny Committee  
9 January 2007

Evidence submitted by the Health Advocacy Partnership (PPI 99)

INTRODUCTION

1. This response to the Health Select Committee Inquiry into future patient and public involvement arrangements is by submitted the Health Advocacy Partnership (HAP).

2. HAP is a not-for-profit Forum Support Organisation (FSO) operating to support PPI Forums that currently operate in Bath and North East Somerset, Bristol, Gloucestershire, North Somerset, South Gloucestershire, Swindon and Wiltshire. These forums monitor the activities of acute trusts, a reconfigured ambulance trust, mental health care trusts, both reconfigured county and unitary based primary care trusts, and a specialist national trust.

3. HAP is a member of Volunteering England; the Democratic Health Network (operated by the Local Government Information Unit of the Local Government Association); and the South West Rural Network.

4. Previously, HAP has contributed responses to the Department of Health’s consultations on the Our Health Our Care Our Say White Paper and also the subsequent consultation on A Stronger Local Voice.

5. This response is based on experience acquired by HAP staff over many years of supporting public involvement under both the former Community Health Council and current PPI Forum arrangements. Though written from a support organisation perspective, we have tried to outline a practical vision of how future public involvement might effectively engage with local communities and individuals.

What is the purpose of patient and public involvement?

6. The purpose of patient and public involvement is to contribute the views of local communities, voluntary sector groups, individuals, service users and their carers to the design, development, delivery and assessment of local health and social care services. However, patient and public involvement is truly effective only if it is perceived that service providers really do take account of the comments made in their service planning, implementation and delivery decisions. There are still too many examples of NHS providers perceived as carrying out “tick box” consultations, which ignore local resident views. Such exercises are often viewed as shams because the local perception is that decisions have already been made. There are also examples of Trusts using current statutory PPI mechanisms—Forums and overview and scrutiny committee (OSC) arrangements—as a substitute for real involvement in decision making.

What form of patient and public involvement is desirable, practical and offers good value for money?

7. The credibility of future public involvement lies in the public knowing that the proposed LINk arrangements will be permanent and not transient, and that participants in public involvement are voluntary and independent from service provider influence. The attempt in the Local Government and Public Involvement in Health Bill to address the main shortcomings of the present public involvement system and to firm up the link between health and social care is welcome. The devil will be in the detail of how exactly the duties on providers will be delivered and how providers will be held to account through OSCs and the proposed Local Involvement Network (LINk) arrangements.

8. The shortcomings of the present patient and public involvement system are perceived to be:
   — it ties statutory involvement arrangements through Forums into individual local health Trust providers;
   — it breaks the ability to track the experience of patients and their carers through their treatment pathway when more than one Trust provider is involved;
   — it exposes voluntary Forum members to local “political” and “interest” pressures from within local communities, pressures from Trusts to address NHS agendas;
   — it limits member ability to take more strategic views of local health care provision;
   — neither PPI Forums nor local OSCs are perceived by local communities and residents as being inclusive or representative; and
the differing approaches and priorities of both Forums and local OSCs fail to deliver cohesion and any strategic vision of the health and social care needs of local communities, which enables Trust providers to adopt a divisive “tick box” approach to their public involvement role and dilutes the voice of local people.

9. Successful public involvement needs to be the eyes and ears and voice of the public. It can only partially be viewed as customer care activities, for it must adopt a more “critical friend” relationship with NHS or other service providers—being ready to both commend and challenge as appropriate. This can be integrated into other forms of citizen involvement to achieve good value for public money. Desirable and effective public involvement must be fully inclusive, offering practical ways to enable all local communities, interest groups and individuals to contribute their views—in ways that are most convenient to them—about the provision of their local health and care services. It is highly desirable that the public involvement is seen by the public and service providers alike as a vital element of both commissioning and delivery of health and social care at the community level.

10. The NHS needs to recognise that Trust structures to deliver such services are largely irrelevant to the local population. What is important to residents is the timely and efficient free delivery of quality health and social care at the point of need—with access to appropriate Trust contacts to raise issues of concern or complaint. Desirable and practical forms of public involvement can deliver good value for money but only if they actively seek to integrate the feedback and contributions of all those with an interest in health and social care provision.

11. A range of public involvement activities can work together within local communities to secure high quality health and social care services. There is evidence that statutory PPI, scrutiny and regulatory bodies can work with other interest and voluntary sector groups, local initiatives such as Expert Patient Programmes, Friends groups, and also Foundation Trust membership and governing bodies. It is desirable that public involvement is perceived to have proactive geographic and strategic responsibilities in relation to the design and development of health and social care services to reflect the real experiences of patient treatment, in addition to a reactive role to comment about the delivery of local services. It is therefore important that public involvement has the capacity, statutory powers and professional support to track health and care services within communities, irrespective of provider delivery involvement—with the added value ability to become a national, regional and local voice of the public.

12. Local public involvement initiatives must have the ability to contribute the public perspective to the activities of OSC scrutiny reviews and inspections and reporting by regulatory bodies—such as the Healthcare Commission’s Annual Health Checks—and to respond with a public view to service crises as they arise. This can practically and effectively be achieved through public involvement monitoring and report activities, supported by lay visits and local surveys. However the delivery of desirable, practical and value for money public involvement can only be achieved if it is perceived by local communities to be effective in influencing the decisions of service providers. Effective public involvement cannot exist if Trust, local council and other service providers only pay “lip service” to their responsibilities to involve local people.

Why are existing systems for patient and public involvement being reformed after only three years?

13. It is reasonable to question if value for money has been achieved from the expenditure of public funds on public involvement over recent years. If data were available, it would be interesting to carry out a best value comparison of public spending for the last three years of Community Health Councils (2000–03) with the first three years of PPI Forums (December 2003–06) in terms of the public involvement outcomes achieved and their impact in influencing change within the NHS. The present franchising arrangement to support PPI Forums adopted by the Commission has created an unacceptably high level of bureaucracy and associated costs without delivering a consistent approach to public involvement across England. There is not even a common procurement approach adopted with Forum Support Organisation contracting arrangements, resulting in very different support arrangements being available to voluntary Forum members.

14. The remit of current PPI Forums is linked to monitoring a single Trust provider and excludes social care, thereby limiting their ability to accurately reflect real patient treatment experience. Current membership of Forums does not accurately reflect the diversity, interests and health needs of local communities. Experience indicates that a significant number of Forums have struggled over the past three years to maintain the requirement of at least seven members as described in clause 2(1) of the Patients’ Forums (Membership and Procedure) regulations 2003 (SI 2003 No 2123).

15. Very low numbers of voluntary members—most of whom work very hard on an individual basis to perform the requirements of their appointment—often result in Forums being exposed to “political”, “interest”, and even personal agendas. This can make it hard for Forums to respond effectively to the difficult decisions that Trusts are making to address their funding, operational and resource pressures.
16. The integration of health and social care necessitates changes to public involvement arrangements at local level. A review of the current public involvement system is therefore welcome. It is very important, however, to draw upon the evidence of good practices developed over many years by Community Health Councils and most recently by PPI Forums.

How should LINks be designed, including:

Remit and level of independence

17. The remit for LINk activity should be to monitor and report from a public perspective, with recommendations, on both the commissioning and delivery of health and social care facilities and services to their local communities. Use of current technology and on the ground resources can enable communities, groups and individuals to have easy access to their local LINk for information about health and social care provision, and to share their comments. Local resources and support must be available to enable those without access to technology to contribute in other ways.

18. Analysis of future public involvement activities shows that every LINk across England will need to consider a wide range of issues of health and social care provision, which fall into seven common themes:
   - acute care;
   - ambulance care;
   - community-based care;
   - continuing and chronic care;
   - mental health care;
   - public health care (and health promotion); and
   - social care.

19. Patient treatment experience often crosses one or more of the above themes. Participation by more than one service provider in this treatment experience causes confusion. It must therefore be a remit for public involvement to ensure that individual care management, accommodating all of the various aspects of service provision, are efficiently delivered for the benefit of patients, their carers and relatives, and the public purse. There is also the common theme of addressing the funding, management and resource pressures facing service providers. Whilst it is possible to address these separately and in isolation, such an approach fails to tackle the “knock-on” impact of isolated decision making on other service delivery and detracts from the need to provide integrated, seamless health and social care within a community. Another remit of public involvement must be to ensure that adequate and easily accessible information is freely available to bring about a significant culture change in service delivery and ensure that communities, local residents and service provider staff are in a position to make informed choices and decisions.

20. It is important that providers properly engage at an early stage of service design with local public involvement. It therefore becomes necessary to overcome the problems of perceived “confidentiality”, which frequently cause providers difficulties with early disclosure of their plans. This might be overcome by making future Local Involvement Networks (LINks) arrangements also subject to the provisions of the Public Bodies (Admissions to Meetings) Act 1960. By making LINks responsible for a geographical area rather than provider based, it will enable local public involvement to retain independence from Trust and other provider organisations.

21. Independence from provider interests does not move LINks outside either the NHS or local government. Appropriate governance arrangements will be needed to facilitate relationships between participants within each LINk, with other health and social care stakeholders, and to drive forward constructive activities with measurable outcomes. A Code of Conduct for participants with a Complaints Procedure are considered essential tools in any governance arrangement.

Membership and appointments

22. It is important that LINks are perceived to be as inclusive as possible. Though each LINk will differ according to local needs, there are enough commonalities of approach nationwide to enable a basic job description and code of conduct framework for participants to be formulated.

23. It is essential to ensure commitment to LINks by developing a “sense of belonging” where each contribution is valued, and participants receive feedback about the effectiveness of their public involvement in influencing service provider decision making. There needs to be no limit to the numbers that can participate in LINk activities—either in relation to local health and social care provision or by contributing to commissioning, delivery or ethical debates and decision making over wider geographic areas. Most people are currently engaged in public involvement because they have or have previously had a very personal user or carer interest, or they have an “axe to grind” about some aspect of local health provision, or simply because they like the status and kudos. Effective engagement in public involvement activities stems from personal interest. Participation by communities, groups and individuals is likely to be founded on personal interests according to the issues that seem relevant to their local community at the time.
24. LINks should be able to draw on the experience, expertise and interests of hundreds—even thousands—of local people acting either as individuals or collectively within community or interest groups. Current PPI Forum members should be invited to participate in LINks to make use of their past experience and ensure that committed and continuous public involvement is maintained, especially during the transition period. There must be sufficient flexibility, resources and capacity built into local LINks to facilitate the ability for contributions to be made on an “opt-in, opt-out” basis as appropriate, without any other commitment required from the participant. Participants in the future may simply want to share their experiences or comments; to contribute answers to surveys; to ask questions and have them answered; to attend public discussions or meetings; or they may be willing to contribute their time and energies to some specific activity with clear terms of reference, a limited timescale and clearly defined outcomes.

25. LINk activities can be delivered through a variety of media—electronic, telephone or in person. There need be no requirement for more formal structures operating through committee arrangements that many find difficult to understand and relate to.

26. It is also questionable if the term “member” is appropriate to LINks. Membership implies a degree of exclusivity that is not compatible with facilitating the widest possible involvement of the public in health and social care provision. For the vast majority of individuals, it would be inappropriate to hold any personal data other than basic contact details. Certainly the current bureaucratic application and appointment system to Forums and the requirement for expensive Criminal Record Bureau (CRB) checks should not apply. There is scope for a limited number of individuals—perhaps held on a regional register—to undertake monitoring visits to health and social care premises. These “visiting” individuals should be subject to achieving approved standards—including satisfactory current CRB certification, participation in regular training and periodic appraisal. The criteria could be developed using the experience of the Appointments Commission. Access to individuals on the approved register should be available to obtain evidence to support LINk activities or as part of OSC or regulatory body reviews.

27. There is currently no requirement or incentive for employers to release staff to engage in public involvement activities. This could easily be overcome by making participation in LINks a “public duty” in line with such other recognised activities such as elected office or jury service. Leave of absence for employed members to participate in LINk meetings and activities can only happen if legislation provides for individuals to take paid leave from their place of employment. The support of employers will also be needed to make this happen. Added value to employer and employee might also be enhanced by recognising such public involvement participation for accreditation (external) as personal, professional or corporate development—particularly when linked to defined project activities with measurable outcomes.

28. Clear definition of LINk roles and responsibilities, combined with a degree of continuity of purpose and clarity in communication will also assist to keep participants motivated. This can be reinforced through appropriate training and team building. An added advantage is that the larger the local LINk “constituency” in terms of numbers of participants involved, the less likely it will be that vested interests can exert undue influence on the outcomes of LINk activities.

29. Active and continuous local marketing will be needed to encourage the participation of communities, groups and individuals in LINk activities. Participation must be encouraged in both proactive activities initiated by the LINks, OSCs and service providers and also in the reactive issues that arise from time to time. Experience suggests that LINk will need a defined contact for their local community. This might be shared between a designated officer within the local “host” organisation and an individual nominated by the local LINk—possibly designated within the role of a Chair. Scope also exists for a named Chair to be appointed for each LINk for a predetermined period of time. This individual could be appointed by the Appointments Commission from applicants meeting agreed criteria or, alternatively, subject to election from amongst those registered as participants in local LINk activities.

30. Technology already exists to enable communities, interest groups and individuals to contribute comments, ideas and views on local health or social care provision; or to participate in their local LINk activities in ways they find most convenient and acceptable.

31. Consistent, continuous and high quality training—delivered to national standards—will be required to enable individuals and groups to participate in the activities of LINks. Training should be modular to be delivered electronically or in person through distance learning, seminars and workshops, or individual coaching. Key training will be regular “Induction” workshops delivered locally to describe “what is a LINK”, statutory duties and rights; structure; support organisation and local working arrangements. More specialist training will be required for both LINk participants and “host” organisation support staff to enhance specific skills . . . Training can be delivered “in-house” or commissioned externally. Ideally training should be externally validated and certificated, leading to a recognised qualification that enhances an individual’s personal development and social skills.
Funding and support

32. It is critical that adequate funding is provided to resource and support local public involvement activities, appropriate to each local community. All elements of supporting public involvement should be delivered to national standards.

33. Some core aspects of public involvement are likely to be common, wherever they are delivered—for example providing an interactive information “hub”; creating a brand profile for LINks; supporting aspects of training; participant training, and activities as appropriate, especially for those approved individuals or those “visiting”.

34. The proposal that local authorities with social care responsibilities should commission external “host” organisations to provide support to local LINks is generally to be welcomed. It is essential to provide a real effective “host” organisation with a contractual remit to involve the widest possible cross section of the local community possible—amongst other responsibilities.

35. The Local Government and Public Involvement in Health Bill needs to be strengthened to reflect the Government’s promotion of social enterprise and voluntary sector not-for-profit organisations as providers of such support. It is noted however than funding will not be ring-fenced but provided by means of a “specific grants” paid to each commissioning local authority. Recognising the need to recover their costs to procure and performance manage the “host” organisation, there should be a statutory limit on the amount that a commissioning local authority can “top slice” from their specific grant allocation for public involvement. The level should be subjected to testing and commentary by the LINk in their Annual Report—or by referral to some appropriate other body (Audit Commission or OSC) if deemed by LINk participants to be too high.

36. Funding and support should be appropriate to the needs of each LINk. The “one pot fits all” approach is not appropriate. Funding and resources need to recognise the impact of geography, urban and rural diversity, population density—and particularly reactive public involvement activities arising from local provider action to address funding, reconfiguration and resource pressures.

37. It should be left to “host” organisations to manage the staffing, premises and overhead cost elements of LINk support budgets, performance managed by the commissioning local authority under the contract arrangements. However, the “host” organisation should report costs of providing support to LINK activities to participants, who should be involved in setting spending priorities.

38. LINk activities should be focused on meaningful activities with measurable outcomes geared to meeting the health and social care needs of their local communities within the context of regional/national performance priorities.

39. It is not necessary for participants to be swamped with paper, nor is it appropriate for them to have deep understanding of provider issues, delivery structures or operating pressures. An efficient and effective interactive information “hub” is a vital element of public involvement to facilitate the sharing of knowledge and views. This could best be provided under national or regional contract arrangements, financed on a mandatory “buy-in” subscription basis from specific grant funds. Efficiencies and economies of scale can be achieved through regional and national activities, coordinated through Local Strategic Partnerships. Feedback of how contributions have been dealt with by service providers is essential and should be reported in the public domain and on the information “hub”.

Areas of focus

40. Time and detailed planning is needed to successfully launch local LINK arrangements, drawing on the expertise of the NHS Centre for Patient Involvement and the Centre for Public Scrutiny to learn from the mistakes made when setting up Forums. There must be clear focus of all LINK activity backed up by expert support with clear points of contact. This can be delivered through a Work Plan that sets achievable targets with measurable outcomes geared to the resources and participation available, which would be reviewed on a regular basis.

41. Despite negative media coverage of financial and operational pressures, the NHS remains highly valued in the public psyche. A key focus of LINK activity should be work with local councils at all levels, with voluntary sector and interest groups, and with service providers to foster public interest and involvement in health and social care.

42. Common themes to focus LINK activity are described in paragraph 17. These can be covered through a series of task groups that report their efforts periodically to public meetings in their local communities.

43. The realities of patient choice, support for long-term conditions, the interface between health and social care providers, case management, and out-of-hours services are all legitimate topics for public involvement examination to provide local evidence to underpin national and regional service initiatives.

44. The health sector has often been perceived as a largely silent voice when planning community services. It is important that LINKs are seen to play an active role in local community planning initiatives supported by all tiers of local government. To obtain a complete picture of the local health economy and local treatment pathways, LINKs must focus their monitoring and report activities on both the commissioning...
and delivery of health and social care services. Common and consistent national and regional promotion of LINks through the media must be supplemented by regular, active marketing to local communities through engagement with local councils, voluntary sector and interest groups.

45. The effectiveness of public involvement will ultimately be measured by the extent to which government, local authorities and service providers are perceived by local people to heed and act upon feedback from LINks. There is a role for LINks in active local campaigning to enhance health and social care provision. LINks must be seen to support and assist the public to get their concerns aired. Creating or facilitating a public platform is not the same as “political” campaigning, which is best left to the new role envisaged for locally elected councillors.

46. LINks exist to be the eyes and ears of the public and to get the public’s voice heard— independent from service providers—to report and provide evidence of local concerns. Their strength lies in their statutory rights to be heard, to ensure that answers are provided by service providers, and to refer to others if these are not satisfactory or forthcoming.

47. Continuous ongoing efforts are needed to encourage young people, ethnic minorities and other “harder to reach” groups to contribute in ways they find most convenient. In particular, LINks should start working with young people through citizenship, personal and social education so they become active citizens for life. Other areas of focus for LINk activities are:

- facilitating communication between the public and LINKs;
- providing information and case studies to help participants work effectively;
- covering generic local health and social care issues;
- working with other organisations in Local Strategic Partnerships;
- encouraging people to comment and feedback at “source” of treatment;
- providing “lay” voluntary perspectives to local inspections and service reviews; and
- engaging in Focus groups and public meetings.

Statutory powers

48. Statutory powers of the proposed LINk public involvement arrangements, as outlined in the Local Government and Public Involvement in Health Bill (2007), largely mirror existing powers. Clarification of the “Section 7” duty to consult the OSC on substantial variation and the “Section 11” duty to involve patients and the public in the design, development and delivery of services are generally welcome.

49. The additional power for LINks to receive a response from providers to reports, and from local OSCs to formal referrals, can only enhance the credibility of public involvement as an effective agent for change. The decision to retain the right of access to provider premises for the purpose of monitoring and reporting with recommendations amongst the statutory powers of LINks is also welcome. It would be helpful to recognise provision for announced, familiarisation and short-notice visits in future regulations—and to clarify all the premises that are affected, particularly if public involvement is to be extended to social care and other service providers, including GP and dentist practices. Statutory public involvement powers should be extended to include the 10 Strategic Health Authorities.

50. Social care providers are subject to best value scrutiny under internal OSC arrangements. There should be a statutory arrangement for LINks to receive copies of appropriate reports and to monitor how recommendations are being addressed. The current duty of PPI Forums to monitor the activities and reports of Trust Patient Advisory Liaison Services (PALS) should be restored to the powers of LINks—not least because PALS influence is being downgraded in many Trusts.

51. Many PPI Forum members would argue that there should be a duty placed on service providers to acknowledge and work with future LINk arrangements.

52. LINks should be recognised as a statutory stakeholder within the local health and social care economy, encouraged to operate within parameters agreed with Local Strategic Partnerships and eventually through contractual arrangements delivery through Local Area Agreements.

53. Considerable effort has been necessary to build relationships between Forums and Trusts and there have been many examples of providers seeking to play Forum members off against their OSC counterparts. This needs to be extended to achieve a collaborative rather than competitive relationship. The concept of “best value” being introduced to health as well as social care is welcome.

54. Though public involvement on a geographic basis is largely strategic, it is important to be able to monitor treatment experiences on an individual basis— particularly in relation to care packages that might involve a number of different service providers. There should be a statutory right—with the patient’s consent—to receive details of packages of care in order to independently verify how they are being implemented and the quality of delivery. This could be a specific role for specially trained staff of the “host” organisation—but with anonymous trends being reported to LINks as a basis for future work-plan activity.
55. There should also be a power for LINks to monitor and report on how service providers respond to outcomes of complaints. This is currently lacking in arrangements for support provided by the Independent Complaint Advocacy Service (ICAS). There is precedent for such an approach in the role of the complaints service previously offered by some, but not all, Community Health Councils.

Relations with local Health Trusts

56. It remains the responsibility of service providers to engage with stakeholders, patients and users, carers, and the community as part of the routine customer care activities. The geographic basis of future LINk interests breaks a direct relationship with Trust providers, but contacts will still need to be maintained in order for LINks to carry out their monitoring of the development and delivery of treatment pathways across local health economies. It is important that Trusts recognise the statutory public involvement role of LINks and fully comply with their requests for information and action.

57. Some Forum members would argue that formal stakeholder status should be extended to formalise LINk relationships and even representation with service providers and OSCs. Though this might improve dealings in the short-term, there is a significant risk of conflict of interests arising.

58. It will be necessary for LINks to work together—particularly on ambulance, mental health issues, or specialist service issues—with Trusts to monitor the development and delivery of treatment pathways across local health economies, even when they cross local communities. There is a role for LINks to advise Trusts in the preparation of their patient prospectus, and also to contribute questions for inclusion in patient surveys.

National coordination

59. Ability to contribute to national and regional reviews would enhance the credibility of public involvement as a significant influencer of public policy and service provision. This could be combined with a power to champion, as well as constructively challenge, national, regional and local policies, based on the evidence available from local communities. There is scope—and indeed it may be desirable—for LINks to cooperate at both regional and national level. This might be achieved through local subscription to a LINk National Association, offering a well defined structure that is able to independently administer governance arrangements. An added benefit of national coordination is to enable LINks to contribute in a coordinated way to the national forum of voluntary sector bodies that is being established to work with the Department of Health in the formulation of policy. National—and also regional—coordination is needed to enable LINks to contribute local evidence to campaigns testing provider performance against targets—for example A&E waiting times (Casualty Watch), infection control (Bug Watch).

How should LINks relate to and avoid overlap with:

Local Authority structures including Overview and Scrutiny Committees

60. If LINks are recognised as a statutory stakeholder within the local health and social care economy then they can operate within Local Strategic Partnerships, and eventually can negotiate contractual arrangements through Local Area Agreements.

61. Public involvement in health and social care could be recognised by regulation as an essential element of the community-planning aspects of strategic development, with close correlation to other activities such as spatial and transport planning. This would enable public involvement representatives to share in the work of Regional Assemblies in their activities, participating alongside other independently nominated representatives. There is also close correlation between LINk activities and other well-developed local authority involvement strategies, such as Citizens Panels and focus groups. Scope exists for some coordination of these activities—such as common questions included in Council customer care surveys—to achieve economies of scale in administration costs and resources.

62. The power of LINk referral of issues of concern to OSCs is welcome. At present there is no requirement to monitor how Trust providers respond to OSC reviews and recommendations—though there is evidence that action is taken. There is a role for LINks to carry out this function. This should be extended in relation to OSC reports on council provided social care services to provide an independent view of how such services are delivered.

63. Individuals on the “visiting” register could be contracted to provide evidence from one or more monitoring visits to contribute a public perspective to OSC reviews as required. Involvement of locally elected Councillors—particularly in relation to initiating ‘community calls for action’ on disputed issues of health and social care provision—can be accommodated within the work plans of LINks.
Foundation Trust Boards and Member Councils

64. Dual participation in LINk and local Foundation Trusts should be actively promoted as complementary not competitive activities. Economies of scale can be achieved by local councils and Foundation Trusts sharing the cost of commissioning a locally-based social enterprise “host” organisation to provide independent support for both LINks and Foundation Trust members. It is probably not appropriate for LINks to be directly represented on Foundation Trust Boards or Member Councils, but there should be no bar on individuals serving in a dual capacity. Clear guidance must be available through the Code of Practice to avoid conflict of interest situations arising.

Inspectorates including the Healthcare Commission

65. LINks should provide a public perspective to the activities of regulatory bodies with interest in health and social care. Contributions from Forums are currently an essential element in the annual “Health Check” process carried out by the Healthcare Commission. This role should continue to be performed by LINks. Contributions about the delivery of health and social care within local communities will draw upon evidence relative to all the local Trust and service providers. Whilst composite LINk reports provide useful background information for the Healthcare Commission review process, it will also be necessary to furnish data specific to individual providers. This has very significant resource implications for the LINk “host” support organisation, which should be catered for in the proposed model contract arrangements.

66. There is scope for a joint annual “Health Check” contribution to be made by LINks and their local OSCs. Individuals on the “visiting” register could be contracted to provide evidence from one or more monitoring visits to contribute a public perspective to regulatory body inspections as required.

Formal and informal complaints procedures

67. There is currently no requirement for either service providers or the Independent Complaint Advocacy Services (ICAS) to systematically and routinely share complaint information with PPI Forums, nor is provision made for this within the proposed powers of LINks. There is an added limitation in that details are currently provided only for “settled” cases, which may have taken many months—if not years—to resolve. This frustrates opportunities for early intervention when things go wrong—such as in the extreme cases of Shipman and the Bristol Childrens’ Hospital scandals.

68. Good practice experience of the complaints services of the former Community Health Councils was to report themes of cases in progress. These trends provided an early “call for action” as evidence to underpin work plan action priorities. As previously indicated, this could be a specifically commissioned task delivered by specialist staff from LINk “host” support organisations or ICAS contractors, or a core task delivered at regional or national level.

In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

69. Wider public consultation should always be carried out for any major reconfiguration or service change that impacts on health and social care facilities and/or services provided to local communities. It is recognised that providers need to manage funding, reconfiguration and resource pressures but this does not negate the requirement for public involvement and consultation.

70. Local experience of NHS provider consultation exercises, including those under the provisions of Section 11 of the Health and Social Care Act (2001), leaves much to be desired. Recent local examples include:

- a demand to achieve significant financial savings to address an operating deficit that occurred mid-way through a Section 11 consultation on service reconfiguration;
- closure of community hospital based maternity services by an acute trust facing midwifery staff shortages without the apparent prior knowledge and involvement of the Primary Care Trust which operated the facility;
- media reports of a closure threat to an air ambulance service operated in conjunction with local police, which is funded by charitable donations and not Trust funds; and
- announcement of a new Independent Treatment Centre (ITC) in an area subject to a major Section 11 service reconfiguration consultation, which puts at least five community hospitals at risk of closure—to be located within 20 miles of a newly opened acute Trust hospital operating another ITC, which has recently announced closure of a second ward taking out of service a significant number of beds.
71. These examples, which include actions by the Strategic Health Authority and even the Department of Health, only exacerbate public frustrations and anger. Service providers need to understand the difference between consulting on options and the need to consult again once decisions are made. Experience indicates that wide public consultation on reconfiguration or service options does not itself alleviate the public disquiet that may arise once a decision is taken.

72. It is suggested that a FOUR stage public involvement process should be mandatory:

— The first stage should involve stakeholders, patients and their carers, and professional staff in the development of options to be considered—identifying advantages/disadvantages and including an impact assessment.

— The second stage should involve and consult on the options identified (SIX WEEKS).

— The third stage should be time for the provider to analyse the responses to the public involvement exercise and to make appropriate decisions (FOUR WEEKS).

— The fourth stage should be a further consultation about the final decisions made with clear explanation from the provider about the factors that have influenced their decision(s) and the benefits that accrue to patients, users, carers and the community (TEN WEEKS).

It is recognised that this suggested timetable has time and resource implications—particularly when a provider is seeking to manage an unexpected financial or operational situation.

73. The involvement of stakeholders, patients and their carers, and professional staff in the design, development and delivery of health and social care services should be continuous and a routine aspect of customer care management practices of all providers. The 20 week involvement and consultation timetable suggested above is not excessively more than current arrangements, and if underpinned by statute or regulation could be included in provider planning cycles—even in emergency situations. To rebuild credibility with the public, there needs to be an underlining commitment that—particularly in Stages 2 and 4—public involvement activities are not side-tracked by new factors that might significantly impact on outcomes or the decision making process.

**Conclusion**

74. The views expressed and suggestions contained in this paper reflect many years of staff experience in supporting both Community Health Council and PPI Forum activities. We have tried to present practical approaches to the issues raised by the Select Committee. The Health Advocacy Partnership would be pleased to provide any further information, in person or in writing, to assist the Select Committee with its inquiry.

*Neil Westbrook*
Health Advocacy Partnership

*9 January 2007*

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**Evidence submitted by the Health Foundation (PPI 117)**

1. **Introduction**

1.1 The Health Foundation is an independent charitable foundation working to improve the quality of healthcare across the UK. Our endowment enables us to spend at least £20 million annually to develop leaders in healthcare, test new ways of improving the quality of health services and disseminate evidence for changing health policy and practice. We welcome the opportunity to respond to the Health Committee's inquiry on patient and public involvement in the NHS.

1.2 We believe that patient engagement should be at the heart of any debate on patient and public involvement. We welcome attempts to ensure the NHS involves patients and the public in decisions about how services are delivered locally through Patient and Public Forums, public consultation and by the development of LINks. However, in our view sustainable improvements will only be achieved by improving the patient-clinician relationship so that patients are as engaged as they want to be in their own care.

1.3 If this is to be effective, something of a cultural shift amongst health professionals is also required. We know from experience that the majority of people working in healthcare want to improve quality and are most engaged when they can see how changes have a direct, positive impact upon the care they are delivering. This applies as much to patient engagement as any other form of system change.

1.4 This submission outlines the rationale for improving patient engagement within health services and the argument for enhanced self-care. It also gives an overview of our new £5 million demonstration project, Co-creating Health, which is aiming to provide both patients and clinicians with the skills and knowledge they need to work in partnership for improved health outcomes.
2. ENGAGING PATIENTS IN THEIR OWN HEALTHCARE

2.1 As the first Wanless review concluded, high-quality care, and the most productive use of resources, depends on the population’s full engagement in health. In addition to other emergent approaches that can and do address some of the problems in healthcare, such as improving patient safety and engaging healthcare practitioners in quality improvement methodologies, we believe that healthcare services could be revolutionised if patients, particularly those with long-term conditions, become more engaged in their own care.

2.2 The rationale for ensuring that patients’ and their carers’ views are routinely made available to service providers (both managers and clinicians) is clear. Firstly, an accurate assessment of the effectiveness of care cannot be made without the patient’s unique expertise about their own condition, its impact and the outcomes of the treatment they received.

2.3 Similarly, the insights patients can provide from an external perspective often identify issues which may not be apparent to those working within the system. For example, they may be best placed to recognise weaknesses in the system that may prejudice core outcomes and safety, such as complex transfers of patient information and long, unintended waits.

2.4 However, as outlined in the introduction, there are cultural barriers within the healthcare professions which need to be overcome if patient engagement is to become systematic and effective.

2.5 Our new Co-creating Health initiative, which is described in detail below, has been developed to help tackle these challenges for people with long-term conditions. The following section explains why we have opted for this focus, though other solutions may need to be developed for different areas.

THE CASE FOR SELF-CARE

2.6 An estimated 17 million people in the UK live with at least one long-term condition, with the incidence of chronic disease amongst over-65s expected to more than double by 2030.

2.7 People with chronic illness are frequent and long-term users of healthcare services, with around 80% of GP consultations and 60% of hospital bed days related to chronic conditions. However, day-to-day management of these conditions is largely carried out by the patients themselves, along with their families, making self-care an inevitable characteristic of chronic illness. As research published by The Health Foundation has found, a hierarchical model, in which the patient is the passive recipient of care services, is therefore impractical.

2.8 Similarly, the national patient surveys carried out among patients in NHS organisations in England consistently reveal gaps between patients’ desire for involvement in decisions about their treatment, and their experience. Further research also suggests the UK is lagging behind other developed countries in terms of patient experience.

CO-CREATING HEALTH

2.9 To help identify the best means of improving patient engagement, we have recently announced plans to invest £5 million in a new self-management initiative, “Co-creating Health”. We believe this scheme has the potential to radically transform healthcare for people with long-term conditions.

2.10 Providing responsive, effective services to support people with long-term conditions presents significant challenges for health services, which healthcare professionals cannot address on their own. Many people want to take a more active role in their own care, but clinicians and their patients need to work in partnership to achieve lasting improvements in health. This is what we mean by “co-creating health”.

2.11 To take a more active role in their healthcare, people need self-management skills and easier access to information about their conditions. Our initiative will include a support programme for patients, providing people with long-term conditions with the skills needed in both the day-to-day management of treatment, as well as those needed to work in partnership with their clinicians and navigate services more effectively.

2.12 Patients also need skilled support and motivation from their clinicians, so our initiative will also provide clinicians with the knowledge, attitudes and skills to become effective in supporting their patients to self-manage. Clinicians and patients will also be encouraged to identify aspects of the health system that hinder patients from self-management (eg out-patient appointment systems), so that new services can be designed to facilitate better self-management.

2.13 While the initiative involves work in three distinct areas, the interventions are designed to be mutually-reinforcing and ultimately support the achievement of long-standing improved outcomes. We believe that this is the first time that all three elements have been brought together to support patient engagement.

2.14 The lessons we learn from this demonstration project will be used to inform our future work in this area and we will share our experiences widely.

The Health Foundation
10 January 2007

Evidence submitted by Healthlink (PPI 121)

1. About Health Link

Health Link is a not for profit social enterprise working in patient and public involvement, particularly with people at risk of health inequalities or social exclusion.

1.1 History

It was formed in January 2004, as a successor to London Health Link, the regional association of London Community Health Councils (CHCs) by Elizabeth Manero, ex Chair of London Health Link. The management committee is made up of patient representatives with many years experience in patient and public involvement (PPI). Health Link also operates a network of 125 lay people across all London boroughs, which have a wealth of knowledge and expertise about their local health service and about patient and public involvement. Most are ex-CHC members and many are now on Patients Forums, Overview and Scrutiny Committees or local involvement groups.

1.2 Activities

Health’ Link’s work is project based, mainly under contract to DH, NHS Connecting for Health and NHS organisations, with some grant funding:

— Running a Choose and Book Patient Reference Group for NHS Connecting for Health, to advise on implementation in London.

— Setting up the NW London Patients’ Parliament for North West London Strategic Health Authority (STHA), recruiting and training members from eight boroughs, designing governance materials and Code of Conduct.

— Outreach consultation for London Patients Choice project, on the choice information needs of socially excluded groups. The resulting Taking Soundings recommended how to avoid Choice inequalities.

— Acting on Taking Soundings: with four STHAs, the DH and NHS Connecting for Health, we developed a Patients’ Information Tool, to enable patients to compare hospitals, in response to Taking Soundings findings.

— Cross-government Partnership for Patients: Setting up nine library pilots to test the role of libraries in patient choice, as suggested by Taking Soundings, through a Partnership led by ourselves and comprising the DH, DEFRA, the Museums, Libraries and Archives Council, the London Libraries Development Agency and London Health Libraries.

— Health and Homelessness: involving homeless volunteers in monitoring and improving A & E services from the homeless perspective, in partnership with Whittington and Homerton Patients Forums. This Project was independently evaluated and funded by the Kings Fund. With funding from the Halley Stewart Trust, we are now implementing the resulting recommendations.

— PPI in the determinants of health: working with the London Health Commission to help grass roots community groups to engage with pan-London decision-making bodies on the determinants of health and health inequalities.

— PPI in specialised services: supporting a Patient Reference Group for the London Specialised Commissioning Group.

— Connecting Patients’ Forums to their communities: developing a “Community Connections” approach for two London Patients Forums, facilitating dialogue between the Forums and local community groups supporting disadvantaged people, so the Forums’ work could be socially inclusive.
Our Evidence

This range of patient and public involvement activity has informed our evidence. Our various projects on Patient Choice demonstrate that we have been able to take the patient and public view to policy makers and get policy and practice adapted. In response to A Stronger Local Voice, we undertook a survey of our Network to gather evidence on the lay visiting to the NHS, which the government was proposing to remove when Patients Forums were abolished. We sent out 125 surveys to our London Network and received 420 responses form all over the country reflecting the strength of feeling on this matter. Results of the survey are attached at the Appendix 28 and summarised in paragraph 4.6 below.

What is the purpose of patient and public involvement?

In the 21st century, it is no longer acceptable for public services to be designed for the public; they need to be designed with the public. A paternalistic approach to public services, where a minority decides for the majority, is inappropriate to a modern diverse, democratic society. We consider that patient and public involvement has two purposes:

(a) to bring a general patient and public perspective to the design, monitoring and scrutiny of health and social care services, and

(b) to use the perspective of people at risk of health inequalities to ensure services better meet their needs, and help reduce health inequalities.

If the first objective is met, services will meet the needs of most people and match the expectations of most of the public. For example, hospitals will meet the standards for accessible services which the public expects from the NHS (e.g., waiting times). If both objectives are met, some of the health inequalities which hold the NHS back in its goal of improving health will be alleviated. For example, the perinatal mortality rate for black African women, including asylum seekers and newly arrived refugees is seven times higher than white women. Where these inequalities are caused by inaccessible or culturally inappropriate services, patient and public involvement which draws in the perspective of these women can help make such services accessible to them.

What form of patient and public involvement is desirable, practical and offers good value for money?

Desirability

The desirability of patient involvement is implicit in the recommendations of the Bristol Enquiry and the Wanless Report:

— In 2001 the Bristol Inquiry29 (which investigated the high number of deaths of babies and young children after heart surgery at the Bristol Royal Infirmary between 1984 and 1995) recommended: “The involvement of patients & the public must be embedded in the structures of the NHS and permeate all aspects of healthcare in the NHS.”

— In 2002, the Wanless Report30 (a Report commissioned by the Treasury into the viability and sustainability of the NHS) required “more effective partnership between health professionals and the public.”

Based our experience, three types of patient and public involvement are needed:

— Prospective—in planning services.

— Contemporaneous—in monitoring services.

— Retrospective—in scrutinising whether what was promised has been delivered.

Prospective: The planning of services operates at both strategic and commissioning levels:

— Strategic—strategies for health and social care need to be aligned to health improvement. For example, if young people are involved in designing health strategies then they will expect to be involved in the same way as they grow older, tying future strategic development to a patient and public perspective. If people at risk of health inequalities are involved in strategic decision-making, their interests are more likely to be advanced by those decisions. We are facilitating contact for NHS London with people with mental health problems and homeless people, so they can consider their needs in developing the no smoking strategy for London, improving enforceability of the forthcoming legislation.

— Commissioning—the commissioning of services without patient and public involvement is commissioning with one hand tied behind the commissioner’s back; statistics can be used to determine what services are required but the way in which they should be provided will be largely guesswork by commissioners if they work without patient input. For example, statistics may
inform a health service commissioner that there are high levels of diabetes in an area but only effective patient and public involvement in commissioning diabetes services will help make sure that some Asian groups, who have a greater predisposition to this condition, find these services culturally appropriate.

3.1.2 Contemporaneous: monitoring of services as part of patient and public involvement is important in ensuring that a fair view is obtained of the performance of those services. Visiting rights are vital for this and we are very pleased that the Department of Health reconsidered its decision to remove these. Without such rights, LINKs may ask patients what they think of local health services—unless they are using them at the time. They can ask local marginalised groups what they think of health services—unless they are so marginalised by mental illness for example that they are receiving inpatient care. They can ask patients their views about their experience of waiting for services—unless they are actually waiting in a waiting room at the time.

Much more consistent training and accountability standards are required to ensure that lay visiting is responsive and of high quality and has clear outcomes. For example, government targets require that patients are seen and transferred or treated from A & E within four hours. Only regular monitoring by patients and the public can give a fair view of the quality of the patient experience of that process and the quality of the environment in which it is delivered. This will enable patient representatives to maintain a dialogue about how it can be improved. This kind of monitoring has the capacity to reduce the amount of inspection required because local services are under constant patient review, making it less likely that problems will build up.

3.1.3 Retrospective: Scrutiny is conducted by elected officials, councillors at local level and MPs at national level, and is the way in which the Department of Health or local health and social care providers are held to account on behalf of the electorate for the commitments made to the population, locally or nationally. It is developing slowly in some areas, hampered poor resourcing and the interruptions of local elections. These reforms would be an opportunity to address some of the problems surrounding scrutiny:

— Failure to make Overview and Scrutiny in health a duty on local authorities and include it in performance management of local authorities has led to patchiness in scrutiny and to its complete absence in some areas.

— Lessons must be learned from this “postcode democracy” on health, where some communities have their interests represented in the health service by their locally elected councillors, and some do not. The planned duty to host a LINKs should be coupled with a duty to undertake scrutiny so that local citizens get best value from the patient and public involvement framework, rather than only half the system as happens currently where scrutiny is poor.

— There is no incentive on local authorities to be transparent about any political bias operating in the way in which they would handle the funding for LINKs or the way they currently operate scrutiny (if they do). Political bias was predicted before the establishment of the Scrutiny role for Local Authorities31 and has been demonstrated now that this role has started, as reported to CPPIH by Patients Forum members32. This problem could be addressed by including an explicit obligation on local Councillors to act without political bias in scrutiny, enforced through the Standards Board.

— When a local election is in the offering, OSCs can carry out no scrutiny at all because of “purdah” conventions, unlike CHCs which operated irrespective of elections. There is therefore a perverse incentive for the NHS to push through unpopular changes at this time, free from challenge or referral to the Secretary of State. This interruption in public accountability could be addressed by prohibiting the NHS from undertaking change at a time when scrutiny committees are in suspension, a period which should be strictly limited. Patients’ needs do not change because of elections so election arrangements must reflect those needs.

— The scrutiny of contested reconfigurations remains weak because, even if OSCs use their power to refer such matters to the Secretary of State, she has apparently complete discretion in whether to seek advice from the Independent Reconfiguration Panel and whether to disclose why she has not. This is a serious accountability gap, at a time when such reconfigurations are becoming increasing common and contentious. A duty on the Secretary of State to give reasons for any failure to call in the IRP would preserve her discretion but make its use more transparent and accountable.

3.2 Practicality

Making decisions with patient and public involvement is more likely to result in outcomes which meet patient and public needs. This is a concept which is mirrored in commerce where market research and feedback are essential components of offering what customers want and need, to have the best chance of succeeding in giving it to them. There are some changes which could improve the practicality of the system:

3.2.1 Integration with scrutiny: Scrutiny by elected officials is the way that this success in health and social care, is monitored. It is impractical to expect scrutiny to be effective without close links with patient and public involvement, so the two have to be integrated. The current arrangement where Patients Forums have powers to refer issues to local OSCs or refer to national bodies if local action has been absent or ineffective, provides this integration and should not be lost.

3.2.2 Integration with management: Well designed involvement need not act as a brake on effective management and decision making. Patients Forum members can and do sit on clinical governance committees, audit committees, NHS boards (although less consistently than CHCs for whom this arrangement was enshrined in Department of Health Guidance), tendering panels and recruitment boards. The practice of mental health service users being involved in the recruitment and training of health service professionals is well established. Maternity service users influence maternity strategy through Maternity Service Liaison Committees. Integrated patient and public involvement is practical and well established, although it is true that there have never been any systematic evaluation of its benefits.

3.2.3 Triangulation with the views of people at risk of health inequalities: it is not practical to postpone all strategic decision-making for outreach consultation with people who are socially excluded. A more practical approach is for the views of people who have joined Patients Forums to be informed by their outreach work (such as the Community Connections project described above) with local community groups supporting disadvantaged people.

3.2.4 Equality of Opportunity: Government policies which do not permit equal access to patient and public involvement for disabled people and people from different ethnic groups and health services which are discriminatory for either group can be challenged. For this reason, it is important that people in the relevant population groups are supported to access patient and public involvement. It is impractical to expect the NHS to meet the needs of disabled people and to provide culturally appropriate services without the direct involvement of people affected who have the expertise to help.

None of these components of effective ppi can be delivered without acceptance that:

- Some people will act as proxies for others: Providing there are proper accountability arrangements for patient representatives as well as training that meets consistent standards, the risk of “usual suspects” unintentionally distorting services to suit their own ends, can be avoided. It is the work of patient and public involvement that must be representative, not necessarily the people.

- Suitably trained and accountable patient representatives should have access to wherever patients go in the NHS: to monitor services from their point of view and talk to them while they are actually using services without fear of reverberations. This way full integration with management can be achieved because judgments are based on a shared understanding of reality. OSCs would be able to scrutinize with the benefit of first hand reports on what is happening in services, which they would not have time to obtain for themselves given the breadth of the scrutiny remit and the other demands on Councillors.

3.3 Value for Money

As patient and public involvement traditionally depends largely on volunteers, value for money is high. Competent staff support is essential and enables the best value to be obtained from the system. There is a clear cost benefit to the NHS if there are quality and health improvements as a result of effective patient and public involvement. The Treasury Guidance33 on Inspection of Services makes the important point that the threat of inspection is a valuable benefit achieved at the cost of merely having the inspection system in place, irrespective of how frequent inspections are: “Would the service worsen if there were no direct inspection or no threat of inspection? Potentially, there could be no difference, or at worst, fraud and corruption could become endemic, service quality could spiral downward and public confidence in the whole political system could decline markedly.” Knowledge of the mere possibility of lay visiting would have the same effect.

4. Why are existing systems for patient and public involvement being reformed after only three years?

This remains somewhat of a mystery.

4.1 Patients Forums: It is true that the reshaping of the NHS requires a different focus, with the shift to commissioning, plurality of providers and integration with social care. However, the necessary changes could be achieved with legislative amendment to functions of Forums so their wholesale removal is not necessary.

4.1.2 CPPIH: It seems that an undue level of resources is tied in up the infrastructure of the Commission for Patient and Public Involvement in Health, with its regional offices and staff. The contract management process of the Forum Support Organisations has also not inspired confidence with Patients Forums.

4.1.3 **Budgetary responsibility:** The peculiar way in which the budgets of Forums have been managed lacks transparency and raises questions about accountability. For example, we were present at a meeting of a Forum where the Chair was required to sign off Accounts in public, with “0” as the only entry because the Forum support Organisations held the budget and refused to disclose how it had been spent, citing commercial confidentiality. This could be addressed by proper application of commercial confidentiality.

In our view, disclosure of this sort of financial data involving public money under procurement is largely a matter of timing. Whilst a procurement process is continuing, the amount to be charged by bidders is commercial in confidence. However, once the contract has been awarded, the way in which the public money funding the contract, is spent, should be transparently and freely reported and open to challenge. We suggest that this interpretation be used to make sure that the procurement of host organisations for LINks is transparent and accountable. The bill before Parliament does little to improve matters as it preserves this substitution of contractual accountability for public accountability and leaves budgetary responsibility for the money spent on LINks unclear.

A consequence of removing these elements of the system might well be that Patients Forums would be incapable of survival. As the support system for the Forums is vested in the Commission, it would be necessary to transfer these roles (training, support, performance monitoring, budget management) to another bodies or bodies.

4.2 Substitute arrangements supporting patient and public involvement under the Local government and Public Involvement in Health Bill

4.2.1 **Support Arrangements:** Both local authorities and local commercial or voluntary sector organisations have potential roles substituting for the Commission’s support functions in the bill. The bill before Parliament imposes a duty on authorities to make arrangements for LINks and it is envisaged that they will commission local organisations for this role. There seems to be an element of government “washing its hands” of the troublesome issue of managing transparent patient and public involvement and offering to local authorities and “the market.” In doing so, greater variability will be introduced making performance monitoring, insofar as there will any, harder to implement.

4.2.2 **National Voice for patients:** It is unclear what role the Centre for Patient and Public Involvement and the proposed loose grouping of voluntary sector organisations styled as “National Voice” will have. The other clear consequence of the fragmentation of the CCPIH function to local authorities is the loss of a national statutory voice for patients, which the CPPIH so signally failed to deliver. This result needs to be challenged as it is a significant subtraction from public accountability. The most significant example of how such an independent public body can contribute was Casualty Watch: a national inspection of waiting times in A & E which highlighted some difficult patient experiences and led to the introduction of the four hour target in A & E.

4.2.3 **Local Authorities:** It seems unlikely that local authorities would be sufficiently remote from LINks to undertake the role of contracting for “arrangements” to support LINks, especially given the very welcome extension of the LINks role to social care which is the statutory responsibility of local authorities. We note that the funding for LINks is to be given to local authorities. Whilst appreciating this is a cost effective way of managing the budget for LINks, we are concerned that this means the funds will be vulnerable to being diverted by local authorities to their other activities. For example, in an area where a local authority is experiencing an increased demand for social services, what would be the brake upon them diverting funding from LINks to the direct provision of services? In the absence of such a brake, there is no guarantee that LINks would continue to be provided or that they would be adequately resourced. Thus the very means of finding out what users thought of social care services in difficulties would be removed. With the current bill before Parliament which includes provisions on the standards for Councillors, there may be an opportunity to address some of these matters in the Code of Conduct and to strengthen the protection of funds for involvement.

4.2.4 **Local Voluntary or commercial organisations:** it is envisaged that such bodies will contract for arrangements to host LINks from local authorities. On the face of it, there seems no reason why commercial organisations such as market research companies should not be granted contracts to support LINks. This would run counter to the whole spirit of patient and public involvement, but may be difficult to prevent under procurement rules.

There is a risk of conflict of interest under the new proposals. With the introduction of plurality of providers there is a tangle of vested interests operating in the health service, with provision of services and monitoring of services increasingly both vested in the voluntary sector. It is a clear principle that the person who carries out a function should not be the only arbiter of the quality of the performance of that function. The government agency, the NHS, which provides health care, has never been responsible for exclusively judging its own performance. If the function of delivering health care is to be transferred to a plurality of providers under contract, the function of scrutiny must not be transferred to the same organisations. Although OSCs have a leading role in scrutiny, they cannot perform this alone and must have the benefit of disinterested input from patient and public involvement bodies. To avoid conflict of interest for bodies which may be both delivering services under contract and contributing to scrutiny of those services by hosting a LINKs, we feel that a new model of contractual accountability is needed as follows:
— It is essential that there is a guarantee of independence incorporated into the new “contractual arrangements” with voluntary sector organisations, for them to have any credibility with the public. This might be achieved through eligibility criteria, a Code of Conduct and a transparent, independent complaints process which permits the removal of members of LINks who display bias or commercial interest.

— Contractual relationships with the voluntary sector should be based on the Compact, which includes the following undertaking by government: “To recognise and support the independence of the sector, including its right within the law, to campaign, to comment on Government policy, and to challenge that policy, irrespective of any funding relationship that might exist, and to determine and manage its own affairs.”

— The spirit of this undertaking needs to colour the relationships between the voluntary sector and the NHS, contractual and otherwise. Voluntary sector organisations need to feel secure that they are not compromised in any procurement process because they are active members of LINks and may have come into some sort of conflict with their local NHS. Equally, the local community needs to be confident that its interests are being promoted in an unbiased and transparent way through an independent LINks. This could be achieved through transparent procurement processes and appropriate provision in contracts for service provision.

4.3 Issues for consideration in connection with the reform decision

4.3.1 Risk Assessment: Under Guidance from the Prime Minister’s Strategy Unit, all policy reforms are required to be subject to a risk management, following on from the recommendations after the BSE crisis: “All decisions and processes need to take account of risk. These include policy making, programme and project management, and operational management and decision making;”

The same Guidance requires “openness and transparency”, “a precautionary approach” where risks to the public are involved and that all decisions “are based on all relevant evidence.” It is not clear that this approach has been taken to the abolition of Patients Forums.

The continual disruption to patient and public involvement of sequential reform and the loss of motivation to individual people who have great expertise in ppi and who volunteer their time and commitment to undertake this activity at local level, must clearly be a factor in any such risk assessment. We are pleased that the very considerable risk posed by the proposed removal of lay visiting to NHS facilities, has been reversed. In the absence of draft regulations on visiting, it is of course impossible to judge how restrictive these might be of independent monitoring.

4.3.2 Cost Benefit analysis of the proposals. A cost benefit analysis should be undertaken of the latest reforms, taking account of all the costs incurred to date. We understand that there may still be empty CHC premises in the country that have not been redeployed or disposed of, suggesting a financial penalty on the taxpayer of this continuous reform of patient and public involvement. Such a cost benefit analysis would have to take account of:

— Parliamentary time spent debating the legislation to set up Patients Forums.
— Parliamentary time spent abolishing Patients Forums and legislating for LINks.
— Cost of closing CHC offices and disposing of the estate, including any premiums for the surrender of leases.
— Costs of disposing of CHC equipment (including disabling and junking of computers).
— Human resources support and redundancy costs for CHC staff.
— Set up costs for CPPIH.
— Redundancy costs for CPPIH staff.
— Costs of disposing of CPPIH premises and equipment (including disabling and junking of computers).
— Set up costs for Patients Forums.
— Recruitment and training of Forum members.
— Procurement costs for Forum Support Organisations.
— Costs of disposing of Patients Forum offices and equipment (including disabling and junking of computers).
— Recruitment and training of LINks members.
— Procurement costs for hosting and subsequent contract management, multiplied by the number of local authorities in the country required to undertake the procurement and subsequently manage the contracts.

34 Handling risk: A user’s guide to the Strategy Unit report. Prime Minister’s Strategy Unit November 2002.
— Opportunity costs of the management time in local authorities, the NHS and the Department of 
Health in implementing these proposals, when the previous set has not been evaluated.

We are not sure what evidence the Department of Health has used to cost the benefits of abolishing 
Patients Forums but no doubt this can be factored into the analysis.

5. How should LINks be designed?

5.1 Remit and level of independence

5.1.1 Remit: the extension of the remit of patient and public involvement to social care with the plans for 
Links is very welcome. However, we do not understand how this is to be achieved given the different 
governance for social care and the extra resources required. A draft specification for a host organisation 
would be useful in determining the adequacy of the proposals to meet the important objective of integrating 
governance in health and social care.

5.1.2 Independence: Sufficient independence is needed to enable the LINks to have credibility with the 
public and to be in a strong enough position to create a meaningful position of influence with local care 
providers. This standard could be met through

— Training and standards for LINks member activity.
— The contracting arrangements we have referred to above for host organisations.
— Accountability for Councilors on political bias, through the Standards Board
— Removal of any possibility for health service employees to be part of LINks.

Currently, regulations on membership are not strong enough to exclude NHS employees from influencing 
the work of Forums and the recommendations they make, which is a clear conflict of interest. We are aware 
of one case where a consultant from a Foundation Trust has become a member of a Patients Forum for an 
adjacent NHS Trust Patients Forum.

5.2 Membership and appointments: it is clearly essential for governance purposes that there be some form 
of core membership of a LINks. Otherwise LINks is merely an amorphous fluctuating group of people and 
groups with no leadership and little accountability, which would effectively put all power in the hands of 
the host organisation. This is not patient and public involvement but a classic talking shop, where gathering 
a plethora of views meets the requirement—but doing something about those views is not required. The bill 
is silent on both membership and appointments. In the absence of draft regulations it is very hard to judge 
the LINks proposal at all. Patients Forum members who are interested in being part of LINks should be 
considered for the core role if they undertake appropriate compulsory training.

5.3 Funding and support: as explained above, in the absence of a model specification for the host 
organisation and for LINks in an area and of an indicative budget, it is impossible to judge the adequacy 
of funding. We have commented about on the proposed support arrangements.

5.4 Areas of focus: the resources, infrastructure and competence required to seek views, and interpret 
these into dialogue across the whole of health and social care will be huge. Nonetheless, these functions are 
very important. We suggest different groups within LINks covering different aspects, so that specialist 
expertise is developed without losing the overview maintained by the core members.

5.5 Statutory powers: all the existing legal rights of Patients Forums must be retained as they constitute 
the backbone of arms length scrutiny. We welcome the extension of a power of referral on social care for 
OSCs. The findings of our survey of 237 Patients Forum or ex-CHC members are detailed below and the 
full extract from our Response to A Stronger Local Voice is attached at the Appendix.

5.5.1 Conduct of Visits: there was evidence of close engagement by lay people in the management of their 
local NHS through lay monitoring:

— 76% usually or always talked to patients about their views of the service;
— 81% usually or always talked to staff about their views of the service; and
— 55% said their visits were rarely or never unannounced.

5.5.2 Shortcomings Highlighted: 77% of respondents said that their visiting had highlighted shortcomings 
in services. Issues raised are grouped for Acute (hospitals), Primary Care and Mental Health Services. In 
terms of the patients’ interest, it is striking that issues highlighted would all have a powerful effect on the 
quality of the patients’ experience, including cleanliness, infection control, security, single sex wards and 
waiting times in hospitals and GP surgeries.

5.5.3 Improvements made as a result of visits: The range and diversity of improvements reported by 
respondents as a result of visiting, across all sectors are illustrated on the bar graph overleaf. Improvements 
to the cleanliness, feeding of patients, to sensitivity of care and to patient information, signage and disabled 
access clearly relate very closely to the patient’s experience of care and issues such as infection control relate 
to the quality of clinical outcome. In addition, there is a clear link between shortcomings highlighted and
improvements secured, with 92% of visit reports highlighting shortcomings also suggesting improvements and improvements claimed in 72% of cases. The purpose of the visits was not just to pick holes in the NHS and complain—real improvements were negotiated as a result. This is illustrated on the graph below.

6. Formal and informal complaints procedures

Independent Complaints Advocacy Service (ICAS), the statutory complaints support service set up in 2001 to replace CHCs' informal role, seems to be a largely invisible service. So far as we are aware there has been no formal evaluation of it. After the Shipman tragedy it is essential that complaints are carefully tracked by those who commission and monitor services. We suggest that ICAS has an obligation to feed in anonymised complaints data to commissioners, LINks and OSCS. There will obviously be a resource issue for this additional role.
7. In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

7.1 Section 7: The legal duty to consult the public, with the OSC as the statutory consultee, is the means by which major changes in infrastructure of local services are tested with local communities. Because changes consulted upon will be by nature “substantial”, the right to refer to the Secretary of State for the OSC, is an important one. Since Shifting the Balance of Power transferred more power to PCTs, it is one of the few ways in which the DH can intervene when unwise or damaging plans are proposed locally. The only change we propose to this system is that the referral process is more transparent, as described above. Section 7 is essential because it preserves local NHS infrastructure and avoids services departing from national policy. Unfortunately, it cannot be triggered if the OSC refuses to respond to a consultation in the first place.

7.2 Section 11: We welcome the planned amendment of S.11 to relate to “significant” operational and planning activities. It is not clear however, what this would mean in practice. There is case law on substantial variations under section 7 but the difference between significant and substantial is unclear. It is important to make Section 11 practical for the NHS to implement but not to reduce its remit to such an extent that they can avoid it all together. Some guidance needs to be developed on what significant means, in consultation with users and health and care providers. It is also not clear how the two sections are intended to relate to one another. If thorough consultation under the new Section 11 has resulted in a consensus solution, how could an OSC subsequently disagree under a Section 7 public consultation on that proposal and refer it to the Secretary of State?

Conclusion: there is no clear evidence of the need for reform on quite the scale proposed. The undoubted faults of the current system may well be due to poor implementation of the last set of reforms, rather than poor design of those reforms. Properly designed and implemented ppi, which recognises and builds upon current skills and commitments, has the right powers and governance framework and has the capacity to add measurable improvement to the patient and user experience of health and care.

Elizabeth Manero
Director, Health Link
10 January 2007

Evidence submitted by the Healthcare Commission (PPI 107)

SUMMARY OF KEY POINTS

— The Healthcare Commission has a key role in promoting the engagement of users of services and members of the public in decisions about the NHS and health services. We give high priority to incorporating patient experience into all areas of the regulatory assessment system. Public and patient involvement helps us to ensure that people get high quality services that meet their needs.

— We currently do this through:
  — our patient survey programme, which feeds into our annual ratings;
  — consulting patient groups on how well they believe Standards for Better Health are being met, thus involving patients and the public formally through our assessment processes;
  — seeking input from patient groups to our work programme, both in general terms and in consulting users of services when we look at a specific issue such as learning disabilities or services for older people; and
  — learning from complaints made against the NHS, as demonstrated by our report into complaints, which will be published soon.

We recognise that these methods still need to be developed and expanded.

— We believe patient experience is very important for assessing healthcare and that the NHS is caring but still not sufficiently user focused. The Healthcare Commission want to be in the vanguard of developing methods for understanding and measuring patient experience so as to improve overall healthcare in this country.

INTRODUCTION

The Healthcare Commission welcomes the opportunity to respond to the Health Select Committee’s inquiry into patient and public involvement in the NHS.

The Healthcare Commission exists to promote improvements in the quality of healthcare and public health in England, and has a wide range of responsibilities, aimed at improving the quality of healthcare provided to patients. We have a statutory duty to assess the performance of healthcare organisations, award annual performance ratings for the NHS and coordinate reviews of healthcare by others.
We are committed to making a real difference to the delivery of healthcare and to promoting continuous improvement for the benefit of patients and the public. This response is based upon our extensive experience of engaging patients and the public in our work and assessing the way that other healthcare organisations do this.

1. What is the purpose of patient and public involvement?

1.1 This question suggests two slightly different meanings: what is the point of involving patients and the public; and what purposes can it serve.

1.2 The overriding reason for engaging patients and the public in planning, commissioning and delivering health services—as well as in regulating health services—is that it helps to ensure that people get high quality services that meet their needs. We have found that by involving those who are the intended beneficiaries of health services, commissioners, providers and regulators can:

- gain a fuller understanding of how patients and the public experience health and healthcare, and what they need from health services;
- design and deliver services that meet people’s needs and—as far as possible—suit their preferences;
- tap into lay expertise that health professionals may not have;
- provide information that is relevant and accessible to patients and the public, that will help them make decisions about how to safeguard and improve their health and health care;
- give people more control over their health, their health services and their lives; this in itself is good for people’s health, as there is evidence (see, for example, the Whitehall Study)\(^35\) that a lack of control or a sense of powerlessness contributes to ill-health; and
- in regulating health services, measure what matters most to patients and the public and promote improvements that meet their needs.

1.3 Patient and public involvement can serve a range of purposes, for example:

- helping to decide how local services should be organised; managing expectations and avoiding conflict;
- helping to identify local needs and how they can best be met; identifying gaps in the provision of services;
- changing individual behaviour, to adopt a healthier lifestyle;
- drawing on the expertise and experience of people with specific illnesses/conditions to design services that meet their needs;
- involving people directly in delivering services and/or managing conditions—either for themselves or for relatives or neighbours; and
- helping to decide what information people need and in what formats and settings, in order for that information to be as useful as possible.

2. What form of patient and public involvement is desirable, practical and offers good value for money

2.1 It has been the Healthcare Commission’s experience to date that there is no single form of involvement that suits all purposes. It is dependent upon the desired outcome. There are different kinds of involvement, which have been variously described as parts of a “ladder of participation” or “spectrum of involvement”. These fall roughly into three categories where the role of the patient/citizen is “passive”, “interactive” or “active”. We set out some examples below. This is not an exhaustive list:

Passive
- providing information (health education campaigns, leaflets); and
- researching people’s experiences and opinions (quantitative surveys, qualitative surveys, focus groups).

Interactive
- exchanging views and information through discussion (public meetings, workshops, online discussions, citizens’ forums);
- considering options and refining plans and decisions (deliberative panels and workshops, online Delphi forums); and
- shared planning and decision-making (consensus conferences, citizens juries, “planning for real”).

Active
— devolved decision-making (individual budget-holding, referenda, neighbourhood planning); and
— devolved service provision (self care, third sector delivery, co-production).

2.2 There are many different methods of involving patients and the public. In our experience, the best way to ensure that the form is “desirable, practical and offers good value for money” is to be clear about the purpose, to understand the range of methods available, and to select a method that suits the purpose. For example, if a reconfiguration of local services is to be undertaken in partnership with local residents, it could benefit from engaging them in an informed dialogue over a period of time, leading to a shared decision. Forms suited to this purpose would include a deliberative workshop series, or a citizens’ jury. But if a decision has already been made and you just want to know how local people will react to the decision, the best thing may be to conduct an opinion poll or hold a series of focus groups. It is important not to confuse research and engagement. It is also important to recognise that providing information is a useful starting point for engaging people in a dialogue; but on its own it is not very “involving”.

2.3 The Healthcare Commission has prepared a set of “ground rules” for effective engagement. These apply in most circumstances—see box below

2.4 Healthcare Commission ground rules for engaging patients and the public:

- **Engage Early**
  If you are starting to plan and project, you will need to be sure you are gathering and/or conveying information that is really useful. Ask who is likely to be affected and who is supposed to benefit from the work. Start by finding out what matters most to them and what they need to know.

- **Know what you can change**
  You must be able to take account of what people tell you. That means being clear about what decisions you still have to make, what is negotiable, what you can and cannot change, and where there is choice between specific options.

- **Embed engagement in the work process**
  Engaging patients and the public should be integrated into the design of your project and work plan — from start to finish

- **Include all the right people**
  Think carefully about who should be engaged with patients and the public. Is it a particular group of patients or carers? Is it appropriate to engage members of the wider public? What about black and minority ethnic groups, disabled people and children? You may need to make special efforts to reach out to those who are especially vulnerable to ill health, but whose voices are seldom heard.
Choose your methods to suit your purpose
There are many different ways you can engage with patients and the public. Be clear what it is you are trying to achieve. For example, think about whether you want to carry out opinion research, or involve people in an informed dialogue. Then select one or more methods that will enable you to achieve your purpose.

Provide clear information
Make it clear to those you invite to participate what you are doing and why, including what you can and cannot change in the light of what they say. Provide them with as much information as possible to help them participate fully in a dialogue with you.

Make sure you have adequate resources
Work out how much it will cost and where resources will come from.

Keep things in proportion
Consider the scale of the project, as well as your timescale and budget. Keep your plans for engaging patients and the public in proportion with these factors.

Act on what you learn
What you learn from patients and the public about what matters most to them and what they want to know should, as far as possible, inform and change your work.

Always give feedback
Tell your participants what you have learned from them and what action you intend to take in response. If you do not intend to act on what you have learned, explain why not. Wherever possible, show what has changed as a result of your actions.

3. Why are existing systems for patient and public involvement being reformed after only three years?

3.1 Notwithstanding the admirable work of many Public and Patient Involvement (PPI) Forums, and the obvious disadvantages of changing structures within a short period of time, the main disadvantages of the existing system, based on our experience of working with forums and the Commission for Public and Patient Involvement in Health (CPPIH) over the last two years, are as follows:

— forums can find it hard to be genuinely inclusive, or to reach out to disadvantaged and minority groups, and younger people;
— the current arrangements encourage an “us and them” approach to public involvement. In the worse cases, polarised opinion and mutual distrust diminish opportunities for constructive partnership working and consensus building. This does not help local people to get what they want from local services any more than it helps NHS trusts to provide “patient centred” health care;
— many voluntary organisations, which have much experience of working with patients and the public, have been left out of the dialogue between trusts and forums. The forums have tended to speak for local people, rather than acting as a conduit between trusts and the wide range of patient-led and community-based groups that exist in most localities. The effect can be exclusive;
— the existing system—a complex set of arrangements for patient and public involvement, with a forum attached to each trust and an overarching Commission—may discourage trusts from taking full responsibility for making sure that they engage effectively with their local residents and client groups;
— this is a ‘one size fits all’ model, which may not adapt easily to changing circumstances in the NHS or to differing local conditions;
— as health and social care become more closely aligned, and as there is increased partnership working and shared planning between NHS trusts and local government, it is doubtful whether PPI forums are well suited to bridging the gap between NHS and local government services; and
— the fact that the government and the NHS are trying to reduce the burden of regulation on trusts does not sit easily with the forums’ having a statutory right to visit and inspect local services. The Healthcare Commission carries out inspections and investigations, and has a strong commitment to involving patients and the public in its regulatory processes. It is debatable whether a separate right of inspection on the part of forums is necessary or appropriate.

4. How should the LINks be designed?

4.1 We strongly support the idea of a local involvement network, located in the local authority, which acts as a conduit between health and other public sector organisations, and groups representing patients and the public. This model, recommended by the expert panel convened by the Department of Health, is a facilitative mechanism for engagement, not a new institution that “does engagement” for the area in which it sits. In other words, its remit is to help health and other public sector organisations to reach out into the community; it does not pretend to speak for the community. It is important in our view that the LINk facilitates engagement with independent groups and organisations at local level, and is able to help local voices be heard and heeded without interference. The LINk should safeguard the integrity of the process of involvement, and authenticity of local voices. They should have duties to perform their role as enablers and conduits. We do not support efforts to recreate PPI forums by LINks becoming independent statutory bodies with “rights of inspection”.

4.2 LINks should not be clubs or membership organisations; they are networks. Any local organisation representing patients and/or the wider public should be part of the network. One local organisation—or a consortium—will need to host the network. The local authority partnership with the primary care trust should appoint the host organisation.

4.3 Funding should be secured for more than one year at a time, and should be sufficient to provide resources that will maintain and build the network, and enable local groups to participate in consultations and dialogue with trusts. Funding should be provided for this purpose by the Department of Health. It seems sensible that the LINks should also be supported by the local authority, so that they become the main conduit for patient and public involvement for councils as well as trusts (see below).

4.4 LINks should focus in the first instant on enabling NHS trusts to engage with groups representing users of services and the public at local level. They should facilitate consultation and dialogue about health and social care services. Once established, they should be encouraged to extend their focus, with support from local authorities, so that they facilitate consultation and dialogue about other local public services as well.

4.5 As enabling or facilitative mechanisms—networks, not institutions—LINks should not have statutory powers. NHS trusts should have a statutory duty to engage with patients and the public via the LINks.

4.6 We agree that a LINk should be established in each local authority with responsibilities for social services. Trusts should have a statutory duty to engage patients and the public through them.

4.7 The National Centre for Involvement (NCI) should be responsible for building capacity of LINks and trusts to promote effective engagement with patients and the public. The focus of LINks should be local rather than national. There is no need for a national coordinating body, although it may be appropriate for the NCI to bring them together regularly so that they can learn from each other, as a means of building their capacity.

5. How should LINks relate to certain organisations and avoid overlap?

5.1 LINks should work closely with overview and scrutiny committees and refer issues that seriously concern local groups to them.

5.2 It should be possible for FT members’ councils and boards to participate in the LINk in the same way as other local patient led organisations would do so.

5.3 The Healthcare Commission should be able to engage patients and the public locally via the LINks. It should have a duty to involve patients and the public, via the LINks and other means, in assessing the performance of healthcare organisations, including follow-up inquiries and inspections when it identifies
risks of under-performance, as well as service reviews and audits. The LINks should be invited to coordinate commentaries from patients and the public, through groups and individuals that are part of the network, for inclusion in the declarations made by trusts as part of the annual health check.

5.4 Effective, continuous engagement between trusts and local people via the LINks and other means (including PALs, Patient Advice and Liaison Services) should reduce the risks of complaints arising, but it is not envisaged that LINks would be involved in complaints procedures.

6. In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

6.1 NHS trusts should undertake wider public consultations when they are considering making significant changes to local services. In principle, these consultations should follow the ground rules set out in Box 2.4.

Healthcare Commission
January 2007

Evidence submission from Help the Hospices (PPI 17)

This submission has also been shared with the Help the Hospices user group chair, David Hart. Help the Hospices requests the opportunity to give oral evidence.

1. EXECUTIVE SUMMARY

Patient and Public Involvement is an integral part of the development and provision of hospice and palliative care services. It is an active process, involving the people who receive and experience services. By involving users, it gives them a voice and allows them to speak out and act for themselves. The most valued kinds of involvement are where changes are made reflecting service users’ rights and needs; where people are directly involved in decision making. Good involvement makes a difference and can lead to noticeable change and improvement in people’s lives.

2. INTRODUCTION

Help the Hospices is the national charity that supports the hospice movement, founded in 1984 to provide national support for the growing local hospice sector in the UK. Help the Hospices supports over 220 local hospices across the UK. This support is provided through a wide range of services aimed at helping hospices provide the best care for patients and their families. User Involvement aids our vision which is of a world in which the best possible care is available to all people at the end of life, whatever their circumstances. The Help the Hospices User Involvement Group is a national group of palliative care service users. The group is diverse in terms of ethnicity, geographic location, illness and condition. The group has established itself as a working group to help support user involvement at a local level in the independent hospice sector and to support Help the Hospices develop their own user involvement work. It also gives an opportunity to give something back and share experiences with others. The group is committed to building on its initial progress and developing future work to support Help the Hospices and the work of local hospices. It also monitors and connects with the NHS patient and public involvement agenda.

3. FACTUAL INFORMATION

The Help the Hospices User Involvement group carried out a User Involvement Survey of UK Hospices. The questionnaire was sent to 220 hospices across the UK and 54 completed responses were received. Results were compiled into a report to show the findings and widely made available by email. The results show the importance of User Involvement within hospices. Some users have instigated significant change to their hospices, in areas such as buildings, layout, food, staffing, visiting hours and activities. However, user involvement activities were not in place in a considerable number of hospices. The survey found that hospices have acknowledged that it is important to make developments in this area. Lack of knowledge and resources are key factors of why user involvement did not take place—reinforcing the fact that education and promoting awareness of user involvement is necessary. As a result of the survey half of the respondents agreed to a member of the Help the Hospices User Involvement Group visiting their hospice to start activity in this area, and Help the Hospices held a seminar in 2006 about user involvement with more scheduled to take place in 2007.

4. RECOMMENDATIONS

It is essential that engagement occurs with the patient and public at the end of life to support hospice and palliative care service development. Users should be involved to assist services provided by national and local organisations through
training;
— planning and managing services;
— inspection and service monitoring,
— defining quality standards;
— research and evaluation; and
— producing learning materials;

The voice of hospice and palliative care users ensures services reflect the reality for people with a terminal illness. With this knowledge, hospices can provide better and more appropriate care for their patients.

4.1 A lack of resources is hindering the development of user involvement in hospices. Given that hospices provide care on behalf of the NHS, PCTs should support and resource user involvement in hospice care on the same basis as they do for all their services. This would support for example, education and training and promoting awareness of user involvement. This is part of a general call for hospice and palliative care services to receive a “level playing field” with other service providers in terms of funding, regulation, etc.

4.2 LINks should include hospice and palliative care service representation eg through user groups. There should be involvement of independent hospices in this, with national co-ordination.

Help the Hospices
3 January 2007

Evidence submitted by Herefordshire County Council Health Overview and Scrutiny Committee (PPI 86)

1. What is the purpose of patient and public (P&P) involvement?
   — To gather P&P views and expertise and then respond, in order to better mould services to actual needs.
   — To increase P&P involvement and thence ownership in health services so that P&P genuinely feel they can influence them and therefore be more satisfied with them.
   — To enable effective exchange of ideas—including from providers to P&P—to increase mutual understanding.

2. What form of P&P involvement is desirable, practical and offers good value for money?
   — Make best use of existing P&P involvement—a number of committed and knowledgeable people currently volunteer their time and energies, and these must be nurtured.
   — Broader involvement is desirable—to include people from Herefordshire’s “hard-to-reach” populations such as young people, ethnic minorities (including Travellers and migrant workers), people with disabilities (including physical and learning).
   — A small amount of extra funding—to be routed through the Health Scrutiny Committee—would allow effective and innovative methods of involvement, such as recruitment of “peer” groups to research issues/preferences with their fellows eg young people making a film about health issues such as counselling or sexual health or substance abuse; or people with disabilities researching care home provision as “dignity champions”; or the use of participatory methodology such as “appreciative enquiry” workshops with stakeholder groups on particular health issues.

3. Why are existing systems for P&P involvement being reformed after only three years?
   — Because they were put together in a rush, with little foresight. No-one should be surprised that there have been disappointing outcomes. Some PPIFs—such as our own PCT Forum—have performed well, but this is despite the poor planning that went into designing them nationally.

4. How should LINks be designed
   — LINks should be an effective extension of the health scrutiny function. If there is not integration between these, LINks will not be any more effective than current PPIFs.
   — LINks must work through the local authority and the scrutiny committee.
   — LINks should be empowered by statute to visit NHS and independent health care premises, with the usual provisos.
— LINks should have at least one member from each designated group of service users and potential service users eg young people, ethnic minorities, people with disabilities, older people, etc.

Councillor Stuart Thomas
Chair, Herefordshire Health Overview and Scrutiny Committee
January 2007

Evidence submitted by Hull and East Yorkshire Hospitals Trust PPI Forum (PPI 30)

What is the purpose of patient and public involvement?

1. Healthcare is a service of intimacy, at a time of vulnerability. It depends absolutely upon trust. Patients cede to clinical staff the responsibility for their treatment and care, sometimes in life-and-death situations. Any necessary “consents” are informed by that relationship of trust. That the patient is at the heart of the service, first, last and always, and that there are independent, disinterested and expert patient and public representatives empowered to reinforce this ethos is of fundamental importance.

2. Patient and public involvement is not a pretty coverlet to sling over an unmade bed. It has to be more than mere window-dressing, a sop to a public whose taxes provide the £92 billion for healthcare. The NHS is an iconic institution, synonymous in the public imagination with cradle-to-grave care, as envisaged in the original “welfare state”. Accordingly, PPI has to be fit for purpose, of real integrity. Only thus can it be the requisite sounding board for design, planning, service-changes, and systems’ development, a real opportunity to get-it-right-first-time and avoid the cost, waste and dislocation of rectification. True PPI is a means to safeguard patient care, and assess clinical engagement, and managerial competence.

3. Authentic PPI is the vital means of balancing the power of the professional and the big institution and ensuring openness, transparency and accountability.

What form of patient and public involvement is desirable, practical and offers good value for money?

4. PPI should be local in shape and representation. There must be continuity and follow-through of issues rather than reliance on isolated snap-shots in time. Healthcare deals with the most vulnerable of society and society at its most vulnerable. The highest vigilance is required. PPI needs to be familiar with the patch and its characteristics and be free of the limitations of the one-size-fits-all model so often beloved of Whitehall. PPI representation should be as consistent as it is possible to make it, productive so as to retain members as it is by experience that laymen become experts in the system they oversee. Fragmented involvement is of little use. Diffuse transience achieves nothing. Scrutiny without knowledge is meaningless.

5. In practical terms, public involvement should be manageable in numbers. More is not always better. Many is not best. Problems of communication and of co-ordination then are in danger of reducing PPI to a web of committees and procedures.

6. Volunteers offer best value, for credibility in that volunteers are independent, accountable only to the public, and not in thrall to the system for their careers and livelihoods and in financial terms because given proper authority to monitor with meaning, to have involvement with influence, they will give their skills and time without pay, so long as out of any pocket expenses are re-imbursed.

7. Localism is all. It has to be said that as a national body, CPPIH represents very poor value for money. It has gobbled up the lion’s share of the PPI budget while many Forum-members found that their expenses took a long time to come through and this limited or stalled their work and caused personal hardship.

8. CPPIH has been, with few exceptions, very unsatisfactory. There has been much staff turnover, and constant re-assignment and change of roles, leaving no ownership of ongoing issues. The glaring absence of any evident qualification for the job is astonishing. CPPIH shows little recognition of the competence and skills of Forum-members, many of whom are more able and professional than the CPPIH staff.

9. Education and training provided by CPPIH has been appalling, with “trainers” bought-in for odd afternoons and days. The level of “training” has often been derisory.

10. CPPIH has doggedly ignored the voices of Forum-members, has always been nervous of letting them do the job the legislation empowered them to do. In CPPIH’s dual-role (“supporting Forums” and “advising the D of H”), Forums have come a very poor second. That CPPIH was moribund within six months of the start of the current system of PPI has, unsurprisingly, left CPPIH’s staff anxious for their own futures and overly compliant to the D of H. CPPIH’s representations of the situation with Forums, and the views and wishes of Forum-members, have often been misleading and damaging.

11. There is nothing to be gained by gratuitously abusing the Commission; these points are made solely because it should be understood how much Forums have achieved despite CPPIH, rather than because of it. Had the Commission performed as it should, and the money been devolved to the front line, there is no knowing what Forums could have achieved.
Why are existing systems of patient and public involvement being reformed after only three years?

12. The department of Health argues “the changing nature of healthcare and plurality of provision”. Plurality of provision means nothing to the patient receiving renal dialysis, a hip replacement or emergency treatment in A and E. It should make no difference to PPI. Wherever NHS healthcare is provided, be it by private provider or NHS establishment, current legislation empowers PPI Forums to follow. Where ever a patient is referred for treatment by a PCT, PPI Forums inspect, assess and report. Why change? Why indeed.

13. The CPPIH has proved a sad creature. Supposed to support and empower Forums, it has, at best, disappointed and at worst become a by-word for contradiction, ineptitude and frustration. With the dissolution of arm’s-length bodies, it had to go and this leaves PPI Fs notionally parentless.

14. Meanwhile, as many Forum-members and many MPs recognise, Forums have become ever more effective, exceeding all Ministerial expectations; to the D of H, Forums’ voices are too clear and informed for comfort. Members’ collaboration with each other, exchange of information, and networking with the wider user-community has made them a force to be reckoned with. The D of H has shrunk from the reverberations of this powerful patient-voice.

15. The presence of Forums, one for each Trust, has provided a very real engine for improvement within Trusts. As “critical friend”, Forums have not only identified shortcomings and helped have these addressed but, empowered by knowledge of local populations, their needs, and the patch-wide healthcare infrastructure, have championed their Trust and its services. This has clearly improved the services and stands directly in the way of the D of H’s moves to “market” healthcare and sell it off to the IS. Even the NHS logo is now for sale! To pull off this prostitution of our health service, the D of H needed to be able to convince the public that their NHS Trusts were “failing”. Forums have ably shown that most “failings” are due to meddling from the centre.

16. The information on the proposed LINks, though short on detail, reveals a deep level of ignorance both from the Minister and from within the D of H as to the nature and operation of PPI Fs. For example, Forums already have dual-roles, which cross commissioner/provider boundaries and enable oversight of seamless care. Further, Forums interact with community and user groups, themeing the issues these raise and investigating and reporting as appropriate.

17. The so-called “reform” is driven by the latest Ministerial mantra, health-outside-hospitals. The whole focus of current thinking at the D of H is community, community, community. Moving the platform of PPI to “the community”, the local authorities to whose boundaries the PCTs have been reconfigured, forces this emphasis. However, it subsumes and buries the specialist services. This is, quite literally, highly dangerous.

18. Further, pushing the host-role for PPI away from a central Commission and onto the local authority enables to D of H to abdicate responsibility: any failures, both in the authenticity and credibility of PPI and in the standards of services, will be attributed to “local mismanagement”.

How should LINks be designed?

19. Though the name is unimportant—it is the substance which matters—the talk of LINKs is doing incalculable harm.

20. Remit and level of independence

PPI must have powers to inspect, freedom to decide when to initiate an inspection, a strong line to the D of H to report, and input as at present via the Commentary to the Healthcare Commission. PPI must be wholly independent, of Trusts, of commissioners, of healthcare providers, of local authorities, OSCs, SHAs and central government. PPI must be the voice that is free to say, “No.” Only thus will it have credibility with the public, be able to attract and retain dedicated members and actually get results.

21. Membership and appointments

Membership should be open to all. Those at the hub, actively themeing, researching, and pursuing issues from across the patch should be a core team of ten to twenty. This is as many as will be readily found, able and willing to devote the time on an on-going and long-term basis to making this work. Experience of Community Health Councils and of Patient and Public Involvement Forums proves this to be the case as does “The Response to ‘A Stronger Local Voice’” which received only 500 responses; significantly, half of these from Forum-members themselves. Against a background of ever-increasing activity in all sectors of healthcare (for example, nearly 20 million A and E attendances alone, in the last year) this is an infinitesimally small sample of so-called “interested individuals”. It is simply a myth that “most people want to become involved in PPI”. Effective PPI does not need to contain a “specimen” of every human type: this is not Noah’s ark. Appointments should have the input of Forum-members, as these are ideally equipped to have a realistic understanding of what the work involves.
22. Funding and support

Funding must be ring fenced for the purpose. Having itself succumbed to the temptation to plunder “soft-targets” when money gets tight and robbed training budgets etc, the Department of Health cannot pretend that LINKs’ allocations left within local authority budgets will be immune from similar piracy.

23. Further, ring-fencing will provide a demarcation between “PPI” and “local government” that is more than financial. By ensuring the financial independence of PPI, it mitigates against the taint of politicisation. When it is understood how deeply the Janus-like remit of CPPIH wounded the development and progress of PPI Fs, it will be appreciated how important it to the success of PPI is untrammelled independence.

24. Funding should recognise the level of expense incurred by the members. This varies considerably from a few pounds a month to a couple of hundred, depending on the activity, the amount of travel (both by car and by rail), and the attendance at meetings across the area and outside it. Stays away from home are not uncommon and hotel bills result. Retrospective reimbursement of expenses often causes problems. Members do not always have disposable income and should not have their role and participation curtailed by this limitation. There needs to be a support organisation that is responsive enough to accommodate members’ incurring expense at short notice.

25. Support should be local, and with a public/High Street presence. The profile of PPI and its credibility is hugely enhanced if it is seen to have the importance that is claimed for it. Office skills, to a high standard, are essential for the host organisation. PPI Forums which have been supported by competent FSOs (Forum Support Organisations) have benefited enormously. Those subject to poor and indifferent support have struggled, redeemed by such members as fortuitously have had good IT skills and the time and money to deploy these. PPI should no longer be dependent on luck.

26. It makes sound sense to include as the host-organisations those FSOs which have effectively served their Forums. Forums know which these are and these FSOs are a tried and tested resource. Some very efficient and loyal FSOs have been lost due to CPPIH’s “economising” on contracts and retaining only FSOs which could/would support six or more Forums. This must not happen again.

27. Areas of focus. A local authority area can be very large and contain a great diversity of healthcare provision. Healthcare professionals are governed for practice by the benchmark of competency and rightly so. Those monitoring healthcare also require competence. Put bluntly, you need to know what you are doing and understand what you are looking at. No-one would suggest that having a central heating boiler equips you to understand and inspect a nuclear power station! It is similarly ridiculous to say that everyone can assess ambulance services, mental health services or the services of a big acute hospital. The average individual would not know a DNA from a DOA or PACS from PBR. The old world of bedpans and bandages has been superseded by a multi-million pound industry governed by science and supplied by consortia. PPI has to specialise.

28. It is unrealistic to suggest that one LINk “covers everything”. A dentist does not do gastro-intestinal surgery and a chiropodist does not do anaesthesia. A GP, even a GPwSI, does not undertake major procedures. There are horses-for-courses, and regardless of job-enrichment and role extension etc the professional boundaries, of necessity, remain. This is not job-protection but the protection of the patient.

29. Ambulance trusts operate across many local authority boundaries and most hospital trusts’ services are commissioned by PCTs from several different local authorities. It is inevitable that PPI must revert to functioning in a way which recognises the particular case of the “specialist” trusts rather than have these prey to interactions with a raft of different LINks.

30. Having since the beginning of PPI Forums been a dual-role Forum-member (chairing a hospital trust Forum and being link-member to a main commissioning PCT Forum), I am well qualified to highlight the difference between the nature of services in the primary care sector and those in the secondary sector and the resultant different emphases of the Forums. The primary sector is essentially domestic in character, taking place in the familiar neighbourhood. The PCT PPI Forums deal with opening hours, distribution of pharmacies, dentists’ lists, the physical accessibility and configuration of GPs’ premises, patient information leaflets and so forth. The “specialist” Forums of secondary care, however, work with highly scientific and disciplined systems of great complexity, systems characterised by specific facilities and services found nowhere else, and having no parallels which provide useful insights through vicarious experience. PCTs may directly receive 80% of the money to fund healthcare but half of that is spend by them on hospital services. Put simply, these are different worlds. PPI must acknowledge and accommodate this difference.

31. Statutory powers

As already stated, these are essential. The increased plurality of provision makes it ever more vital that the right of access to all premises where healthcare is carried out is mandatory. The independent sector has been given from the public purse a privileged framework of PBR enhancement and guaranteed-activity payments yet has been quick to invoke the shield of commercial confidentiality. It wants both the toffee and the halfpenny. This mentality signals little hope of access by invitation. Without the right for PPI to visit,
inspect and report, the independent sector will be a sphere with no transparency and no accountability. Public money pays for NHS activity in these establishments and the same scrutiny must apply here. Safeguards and scrutiny must be the same across all provision.

32. Statutory powers of access to and inspection of all providers of healthcare are the minimum required to give PPI any integrity and to attract and retain members. Without these, PPI is a talking shop, a gab-fest. Powers as currently enjoyed by PPI Forums need to be at the heart of the new legislation but with a strengthened right of access, preferably without notice.

33. Relations with local health trusts

Inevitably, the local health trusts are the organisations with the highest visibility in the public consciousness and are the providers easiest to identify. Notwithstanding the enlargement of services in the community, with nurse prescribers, pharmacy prescribers, enhanced care practitioners, GpwSIs etc, the shape of the healthcare scene in terms of institutions and premises will not change overnight, and the bulk of them will remain ostensibly the same. There will be dentists/GPs/health centres/clinics/walk-in centres for everyday use and there will be hospitals for elective procedures and times of crisis. Ambulance services will continue to bring the public from the scene of the accident, whether home or roadside, to the door of the acute hospital, and to the mental health hospital when breakdown is severe.

34. Each of these trusts has its own board, its own management, its own professionals. It is regarded, not least in financial terms, as a business in its own right. It will need to be dealt with as a separate entity. To say that LINks should not focus on “institutions” is to be divorced from reality. To say that the **raison d’etre** is “to follow the patient-journey” is to reduce LINks to a complaints’ bureau and a conglomerate of personal agendas. This is not meaningful PPI.

35. National co-ordination

Belatedly, very belatedly, CPPIH is currently formalising the “associations” that Forums have built between themselves. There have been nominations for a National Association of Forums and elections are soon to take place. Such a National Association will provide a profoundly more authentic voice than has been heard through the assumed proxy of CPPIH.

36. One of the abiding frustration for Forum-members has been the refusal of CPPIH to take up suggestions and requests, CPPIH’s claim to “speak for Forums” when what it propounded was wholly at odds with what Forums were saying. Forums have had to “work round” CPPIH and it has taken a huge amount of determination, persistence and effort finally to impact on decision-makers, having got through the walls that CPPIH put up. National co-ordination must be effected by PPI members, not by external agencies which are surrogates of Whitehall. If for no other reason, this is essential to avoid the taint of politicisation, both for the public and for those enlisted to LINks.

How should LINks relate to and avoid overlap with OSCs?

37. Overview and Scrutiny Committees for Health are locally elected political nominees. They are not initiates of healthcare and have neither the time nor the inclination to be so. Currently, most simply receive formal presentations from the professionals, sometimes as infrequently as six times a year. There is no way that this provides even the most token oversight of healthcare. OSCs need to be informed by troops on the ground and alerted to any issues of concern. LINks, like PPI Forums, will not overlap with OSCs.

38. Many OSCs have allocated, on a permanent basis, places at their meetings to PPIF members and benefited from this. OSCs have been better informed, provided with independent and evidenced data and thus enabled to exercise their powers in an informed way. It is desirable that this should continue and that places for LINks members should become part of the constituence of OSCs.

39. Foundation Trust Boards and Members Councils. By definition, the boards of Foundation Trusts are part of the trust. They belong to the system. The status of “Foundation Trust” makes no difference to the case for independent and impartial and disinterested scrutiny. It is apparent that even non-executive directors of some years service with NHS trusts can be very limited in their understanding of the context in which trusts work. Independence and the objectivity it brings is vital.

40. Formal and informal complaints procedures do not belong within PPI. PALS and ICAS exist to deal with concerns and complaints and the Healthcare Commission acts as the final arbiter when issues cannot be resolved. PPI should assess the services and the system, not fight individual battles.
In what circumstances should wider public consultation (including under Section 11 of the Health and Social care Act 2001) be carried out and what form should this take?

41. It has been suggested that public petition should be the trigger for examination of an issue. This is inappropriate as it comes in to play when the “concern” has already become entrenched. A petition is evidence of a lack of consultation, not a mechanism for it.

42. There are circumstances where it is obvious that consultation is required, the proposed closure of a hospital, or transfer of a service (eg dialysis, audiology) to the private sector, or relocation any distance of a GP’s surgery. But if there is embedded, credible PPI, much of the consultation and opinion gathering will be an intrinsic and automatic part of the process, not an add-on, emergency contingent. The evidence from the patch will be to hand, the affected client-base will be known and their insights included. The greatest threat to ethos of Section 11 comes from the centre, when policy is changed at short notice and steamrollered through. Such imperatives make a mockery of PPI, consultation, and local decision-making.

Ruth Marsden,
Chair, PPI Forum for Hull and East Yorkshire Hospitals Trust
7 January 2007

Evidence submitted by INVOLVE (PPI 98)

1. INTRODUCTION

INVOLVE is funded by the Department of Health and is one of the programmes of the National Institute for Health Research. The INVOLVE group meets four times a year and the membership includes service users, carers, researchers, research managers and practitioners from both the voluntary and statutory sectors. INVOLVE has been promoting active public involvement in NHS research for the last 10 years. Since 2001 our remit was extended to include public health and social care research taking place outside the NHS.

We believe it is vital for members of the public to be actively involved in research. Research which reflects the needs and views of the public in this way, can lead to more relevant research and is more likely to produce results that can be used to improve practice in health and social care.

To this end INVOLVE aims to:

— develop strategic alliances with key organisations
— develop the evidence base for active public involvement in research
— empower service users, carers, patients and members of the public to take an active part in research

INVOLVE has a full time Support Unit which undertakes the practical aspects of the INVOLVE’s work. This includes:

— producing guidance and information on active public involvement in research
— providing advice to researchers, research managers, research commissioners, and members of the public on active involvement in research.
— holding conferences and seminars, and giving talks and workshops for a variety of organisations

Our role is to promote and support involvement within research rather than service delivery. However, many of the arguments for the value of public involvement in research are transferable to public involvement in service delivery more generally.

Below are our responses to two of the questions raised by the Committee.

2. What is the purpose of patient and public involvement?

Over the last 10 years there has been an increasing emphasis by the Department of Health on a patient centred NHS and social care services which recognises the contribution patients and the public can make to both research and service provision. This has been reflected in various documents, for example: Strengthening accountability: Involving patients and the public (2003); Creating a patient led NHS: Delivering the NHS Improvement Plan (2005); Research Governance Framework for Health and Social Care (2005); and the Best Research for Best Health: NHS R&D Strategy (2006).

Patients and the public are the end users of NHS research and services and therefore it is important that they are at the centre of NHS plans. One of the strongest motives service users and carers give for getting involved in research, is to help bring about improvements to health and social care and to improve existing services and treatments. Patients and the public can bring a unique perspective, by offering a view from the “outside looking in”, which is different to that provided by health professionals.
Public involvement can help to:

— identify issues that are important from a patient perspective;
— influence the way services are planned;
— improve services from a patient perspective;
— improve the experience for people who receive services; and
— make it more likely that services are provided in user friendly and acceptable ways.

3. What form of patient and public involvement is desirable, practical and offers good value for money?

Our experience of public involvement in research, provides us with an understanding of the nature and scope of public involvement, which has relevance for public involvement in service delivery.

The public has been involved in research and development for a number of years and in a variety of different ways. For example, this includes:

— identifying and prioritising research topics;
— being part of research advisory groups and steering groups;
— undertaking research projects; and
— reporting and communicating research findings.

Public involvement can range from being consulted about some aspect of a piece of research, through to collaboration in a research team, to research which is actively controlled, directed and managed by the public.

INVOLVE has produced various documents in consultation with the public and researchers which highlight good practice in public involvement, as well as practical issues to consider (eg Hanley, 2004; INVOLVE, 2006; Steel, 2006; Steel, 2004; Tarpey, 2006). There is also an increasing body of literature highlighting principles of involvement in research (eg Telford, 2004; Faulkner, 2004; SURGE, 2005). Much of this work is transferable to public involvement in service delivery. For example:

— avoiding tokenism;
— involving people with direct experience of a condition or service relevant to the area of work;
— taking into account diversity and equality issues;
— working with communities and groups;
— allowing time to build relationships;
— negotiating and clarifying levels and types of involvement of most value;
— offering people a choice about how they want to be involved;
— involving people as early on in a project as possible; and
— planning for sufficient time and resources to support involvement.

Whilst there is a growing acceptance of the value of public involvement both in research and service delivery, systematic research to evaluate the nature, scope, cost effectiveness and impact is relatively limited. As a first step, we are currently developing a web based database of research to identify research that has been carried out in this area as well as other research whose primary focus is a research analysis or reflective analysis of public involvement in NHS, public health or social care research (www.invo.org.uk/invoNET.asp). This will help us to gain a better understanding of the value of different types of involvement.

Note:

— *active public involvement

Active involvement in research is different from simply taking part in a study. It is about research that is done with, members of the public, not to, about or for them.

When we use the term “public” we mean this to include:

— patients and potential patients
— informal (unpaid carers)
— parents/guardians
— people who use health and social care services
— disabled people
— members of the public who are the potential recipients of health promotion programmes, public health programmes and social service interventions
— groups asking for research because they believe that they have been exposed to potentially harmful circumstances, products or services organisations that represent people who use services

Sarah Buckland  
Director, INVOLVE  
January 2007

4. REFERENCES

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Evidence submitted by the Keep Our NHS Public Campaign (PPI 66)

INTRODUCTION

Keep Our NHS Public is a non-party political national campaign. Its principle aim is to resist the privatisation and commercialisation of the National Health Service and to promote its future development as a truly public service. It brings together medical professionals, health service unions, academics, user groups, concerned citizens and politicians such as former health secretary Frank Dobson.

SUMMARY

We welcome the opportunity to comment in the light of new government proposals for patient and public participation. The proposals in their current form significantly curtail the statutory right of patients to participate in strategic decisions affecting their health services. Under them, patients and the public will undergo a fundamental shift in status—from citizens empowered with legal rights to participate in strategic decisions affecting their health services—to consumers, merely able to comment about the services on offer and possibly with more choice to shop around, if they are able to afford transport costs. The new proposals go hand in hand with privatisation and mark the end of the NHS as a democratic institution

EVIDENCE

1. What is the purpose of patient and public involvement?

The purpose of patient and public involvement is to ensure that the needs and wishes of patients and potential patients are taken into account in the planning, development and provision of hospital, primary care and community health services.

2. What form of patient and public involvement is desirable, practical and offers good value for money?

2.1 Any system of public/patient involvement must provide patients with a strong, independent, collective voice and clear statutory rights to ensure the interests of patients are not swept aside by short term financial, political or corporate considerations. Many in the field consider that CHCs were far stronger in this respect than their replacements.
2.2 The essence of consultation is the communication of a genuine invitation to give advice and a genuine receipt of that advice. All NHS bodies should be required by law to observe this principle, otherwise consultation will continue to be a sham and a waste of money. The government itself has a poor record in this respect. For example, the proposed new law requiring PCTs to publish “regular reports of what they’ve done differently as a result of public opinion or explain why they are unable to respond” gives managers a statutory right to ignore public opinion. Similarly, the Secretary of State’s decision to back NHS managers wanting to make unpopular closures and service reconfigurations (HSJ 30 November 2006) and to foist Independent Treatment Centres into areas that don’t want or need them (Health Committee report Volume 1 para 131–134, 13 July 2006), belies the official support for patient and public involvement.

3. Why are existing systems for patient and public involvement being reformed after only three years?

3.1 According to the government, greater emphasis on services being provided in the community and being developed and commissioned jointly with local government requires a new system—one that will focus on strategic commissioning and the “whole person experience” rather than on individual provider organisations, as with patients’ forums (Response to “A Stronger local voice”, December 2006). However, an anonymous health expert has told the Local Government Chronicle that the new proposals are all to do with the marketisation of the NHS and the need to “prevent people who are critical of private sector involvement from making inspections and using them to cause trouble” (Local Government Chronicle 20 July 2006). Many aspects of the new arrangements support the latter view (see below).

4. How should LINks be designed?

4.1 Remit and level of independence

4.11 LINks, primarily, will be consumer bodies, gathering the views of local groups and individuals in the community about their experiences of the health services on offer and conveying those views to commissioners, providers, and official regulators (Government response to “A stronger local voice” December 2006). Their remit is therefore much narrower than that currently enjoyed by Patients’ Forums with respect to individual trusts (NHS Reform and Health Care Professions Act 2002, s.15(1)–(3)).

4.12 We believe the remit of LINks should be broadened to include a duty to monitor and review at first hand the range and operation of services provided by NHS trusts and private providers in their area; to provide advice and information about those services to patients and their carers; to provide advice and support to patients wishing to make a complaint and to promote public involvement in consultation processes.

4.13 LINks must be seen to be independent of NHS management, to restore trust and encourage public participation in their activities. Instead, current proposals require LINks to act proactively with commissioners and undertake research and evidence collection on their behalf, where practicable. They will have a duty to co-operate and co-ordinate their activities with official inspectors and regulators. Their right to visit and inspect health service premises will be restricted to that of “a tool for validating the evidence they’ve collected elsewhere”. In addition, the new health and adult social care regulator will be able to intervene to prevent inspections which “could impose an unreasonable burden on the institution providing care”. And if a LINk becomes a single issue campaigning group, their host organisation could be liable to sanctions or removal of their contract for failing to ensure that the LINk represents the views of the whole community.

We believe these restrictions, which effectively give NHS organisations the upper hand, compromise the independence of LINks and should be removed.

4.2 Membership and appointments

We support the proposal for LINks to have a wide diverse membership that includes nominees from voluntary and community groups as well as individuals who put their own names forward. But we believe local political parties should also be allowed to make nominations. Such individuals are likely to have good contacts with their local communities and be willing and able to make a positive contribution. They are no more likely to show bias than existing eligible groups such as members of foundation trusts, trust-based patients groups or voluntary providers of NHS services.

4.3 Funding and support

Local authorities should receive extra, ringfenced funding to support the setting-up and effective running of LINks. Host organisations should be independent of the government and the local authority and this independence should be guaranteed in their contracts. They should not be discouraged from implementing agreed LINK policies through fear of losing their contracts.
4.4 Areas of focus

LINks should be able to focus their activities on any area relating to the provision or commissioning of health care services in their geographical area. Their actual agenda should be determined locally, reflecting their own priorities or areas of concern. LINks should not necessarily be required to take into account the priorities and plans of other organisations as this could lead to duplication and a tendency to miss important aspects of their own research.

4.5 Statutory powers

We believe LINks should have the same visiting rights and rights to information currently enjoyed by the patients’ forums. They should also have the right to be informed of and consulted over plans affecting the planning, development and provision of services. However, under the current proposals, LINks will have reduced statutory powers compared to patients’ forums. For example, they will have the right to require NHS organisations, including private providers, to provide them with information and to respond to their recommendations. But they will only be able to enter and inspect NHS health care premises (not private) under limited and tightly controlled conditions.

4.6 Relations with local health trusts

LINks should form good working relationships with local trusts but, to safeguard their independence, they should not be funded or permitted to undertake research or other work on their behalf.

4.7 National coordination

LINks should be funded to set up a national group that would co-ordinate their findings and provide them and their host organisations with support and advice, along the lines of ACHCEW, the Association of CHCs for England and Wales.

5. In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

5.1 Under current law, NHS organisations are required to involve and consult:

(a) The overview and scrutiny committee of the local authority on any proposals for substantial development or variation in the provision of the local health service

(b) Service users and potential service users either directly or through their representatives in the planning, development and operation of services.

(Health and Social Care Act 2001, section 7 and 11 respectively).

5.2 We support the fact that formal consultation on substantial changes requires a health authority or PCT to publish a consultation document that contains sufficient information and allows enough time to enable the public to make an intelligent response. We also support regulations under section 7 giving overview and scrutiny committees the right to refer disputed consultations to the Secretary of State or, in the case of foundation trusts, to the Monitor. We believe section 11 should provide patient representatives with the same right of appeal, to ensure managers cannot disregard the results of a consultation without political accountability.

5.3 Unfortunately, the government has recently legislated to repeal Section 7 of the Health and Social Care Act 2001 that provides for regulations on consultation with overview and scrutiny committees (National Health Service (Consequential Provision) Act 2006, Chapter 43). The latter comes into force in March 2007. In addition, it has introduced a new bill which, if enacted, would limit consultation under section 11 to (a) the planning of the provision of services and (b) to changes that significantly affect the range or manner of delivery of services at the point of use. (Local Government and Public Involvement in Health Bill November 2006).

5.4 Such legislation would allow an NHS organisation to by-pass public consultation on substantial changes, including the awarding of contracts to multinational corporations, if managers could argue that the proposals would not affect the delivery or range of services on offer at the point of use. We deplore the move to significantly curtail the right of the public to statutory consultation.

Keep our NHS Public

January 2007

Evidence submitted from the Chairs of Kensington & Chelsea PCT Forum and Chelsea & Westminster Foundation Trust Forum (PPI 14)

This is a submission from the Chairs of Kensington & Chelsea PCT Forum and Chelsea & Westminster Foundation Trust Forum. We will follow the format of your terms of reference. Due to time we have not been able to canvass your words with all our members but have been discussing the issues in our meetings since September when CPPIH raised them.
Purpose of patient and public involvement?

1. To listen to the voice of patients in the locality and ensure their views are included in service provision and planning of all local health services.
2. Thus to raise public influence in improving administration as well as effective treatment.

What form of patient and public involvement is desirable, practical and offers good value for money?

3. Volunteers with an interest in local health grouped in one local voluntary and independent organisation, backed by an efficient administration with good local contacts.

Why are existing systems for PPI being reformed after only three years?

4. Firstly the Government had set up CPPIH before reforms had their full impact on the NHS. It proved out of touch with local needs as seen by the Forums. Secondly because of the poor design of CPPIH the Forums are only gradually beginning to achieve their purpose. They have influenced the Trusts and acquired valuable experience which can be used.

How should LINKs be designed?

5. They must be seen to be part of the public response to the NHS and so independent of statutory bodies (PCT and Borough Council). As far as possible they should be democratic in recruitment and governance and, like other voluntary associations, dedicated to their mission. Funding should be agreed purpose-built for a LINK. So should staffs in their motivation. They should focus upon Local Government Areas and the communities within them. They should have powers to enter, research and inspect, and get answers. Relations with local health Trusts should be based upon mutual respect and respect for patients. National coordination may help by gaining other models of effectiveness but central domination could threaten the localness and independence of LINKs.

How relate to and avoid overlap with:—

6. LG structures including OSCs? Council officers should be trained (probably through the CEO) to resource and support the Borough Health actions of the LINK. An alliance with the OSC seems natural. Foundation Trust Boards and Members Councils? Should relate to Links as now PCTs try to Forums. However the funding/commissioning as now by PCTs will need examining. Inspectorates including Healthcare Commission? LINKs should use them but check carefully information which varies from their own. Formal and informal complaints? LINKs will need to promote actively better standards and more usable information by professionals from PALS and ICAS.

Wider Public Consultation?

7. Wider consultation should be used when it is necessary to prove to the public that new actions by Trusts or Borough Social Care Services singly or together will benefit the public. LINKs should act as public advocates in each consultation. They should also be ready to insist on layperson’s language.

Kensington & Chelsea PCT and Chelsea & Westminster Foundation Trust Forum

29 December 2006

Evidence submitted by the Kettering General Hospital Patient and Public Involvement Forum (PPI 7)

This submission of evidence is on behalf of the Kettering General Hospital Patient and Public Involvement Forum of which I am the Chair. We realise that in answering the points raised in your inquiry that some of our answers are repetitive. However we feel that it is essential to reinforce our views.

We are not making a request to give oral evidence but would be quite willing to do so if you should think it necessary.
**SUMMARY OF THE MAIN POINTS**

1. The purpose of patient and public involvement is to involve as many people as possible in having a say in their health and social care.

2. If membership is too large LINks will be unwieldy and expensive and not good value for money.

3. People’s opinions should be sought on a wider basis but the organisation representing these views should be more streamlined.

4. The remit of LINks should be to monitor the whole patient journey and care in the community. LINks must be independent of local councils and must not be political.

5. Membership of LINks must not be too large as this will make the organisation unwieldy; however it needs to be large enough to allow for further sub-committees to continue the already established work with Acute, Mental Health and Ambulance Trusts.

There should be a manageable number of members that consult with a wider public and voluntary organisations.

6. Funding for LINks must be ring fenced.

7. An area focus should be maintained through locality based sub-committees; otherwise a local focus will be lost.

8. It is essential that LINks have powers of monitoring and audit.

9. It is important that existing relationships with local health Trusts are maintained in the new system.

10. National co-ordination is important however this does not need to be established immediately.

11. PPI Forums already have established links with OSC’s, Trust Boards, the Healthcare Commission and PALS and local Voluntary Organisations. These links must be maintained. The Forums work with local authorities through the OSC.

**FACTUAL INFORMATION**

We are particularly concerned to emphasize the close links we have with Kettering Hospital and the cooperative work that has been established. Forum members sit on several hospital committees to represent the patient and public view, the Chair and Vice-Chair attend Board Meetings, and the we have reinforced the campaign for infection prevention and control by promoting with presentations and visual displays what the public can do to contribute to this important matter. We would like to think that this could be maintained by us as a sub-committee of LINks.

We also feel that it is important to organise the LINks set up in a way that will not dissipate Patient and Public Involvement. This is why we consider a core membership with wide reference to the general public is a good approach.

We would also emphasise our links with OSC’s, Trust Boards, the Healthcare Commission, PALS and local Voluntary Organisations. It would be advantageous to maintain and build on these as a part of the new LINks.

_Sheila White_
Chair, Kettering General Hospital Patient & Public Involvement Forum

_18 December 2006_

**Evidence submitted by Kingston PCT Forum (PPI 80)**

1. **PURPOSE**

To ensure that patients and public (better just as public) have a say in health provision in their local area, bearing in mind that much secondary and tertiary and mental health care may involve bodies outside the area of the LINK.
2. **VALUE FOR MONEY**

Not possible to say unless a measure for VFM is created. Presumably unpaid (and substantially retired??) groups commenting on health and social care are VFM.

3. **LINKS**

Total independence. Remit (in theory) to represent the views of the people of the area in respect of health and social services.

4. **MEMBERSHIP**

This is a very grey area. In order prevent interest groups “taking over” “independent” members should be a majority. Very unclear as to which “voluntary organizations” should be members—no definition of “membership”. Eg British Heart Foundation is a national body with, it is assumed Trustees but, like others, has local outlets. Who would “represent” it? Presumably not paid officials but, if not, who? The local area will hold a number of people who are not represented by any local body but who have relevant views and belong to national bodies.

Initial appointments will be by Host Organizations, without Local Authority involvement (and, although they are likely to be local voluntary organizations there would seem to be a conflict of interest if they seek to be members as well) and thereafter by the LINK. There seems to be a need (and talking about “local arrangements” will not do) for a permanent central LINKs “executive” in each area. Given what the LINK is expected to do and the potential size of its permanent and temporary membership it seems as if a few of this group will need an honorarium.

5. **FUNDING**

It is disappointing that the funding will not be ring fenced.

6. **FOCUS**

It is likely that the focus will be on hospitals and PCTs and omit other areas as less visible

7. **NATIONAL COORDINATION**

This seems essential. Local bodies cannot (or if they do, there will be enormous overlap) run training courses, obtain CAB checks etc.

8. **RELATIONSHIPS**

It is understood that there are about 100 bodies that already have powers to inspect “Health” so there will be a substantial overlap. It seems unlikely that OSCs will confine themselves, as suggested, to matters of commissioning.

It seems likely that patient and publics are more likely to complain rather than praise. LINKs could look only at general areas and would have to refer complainants to existing procedures, using information from them to guide workplans.

9. **PUBLIC CONSULTATION**

Personal experience shows that Trusts carry out substantial public consultation—with the main groups attending being NHS staff and patients with specific interests—and the totals being very small. On the whole it seems that Forums have not been successful, despite best efforts, in rousing public interest and it is not clear how LINKs will be more successful, other than involving interest groups which do not represent “the public” (potential patients) though they may have good contact with current patients. This does not necessarily reflect on the Forums—Local Elections indicate that public interest, other than in high profile cases, is difficult to engage.

*Gareth Jones*
Chair, Kingston PCT Forum and also on behalf of Kingston Hospital Trust Forum.

*January 2007*
Evidence submitted by Leicester, Leicestershire and Rutland PPI Forum (PPI 64)

SUMMARY

We believe that our PPI Forums have built up an effective network in our area, within which we can utilise the considerable experience and expertise that we have gained over the last three years, to monitor and influence the delivery of NHS services to our population.

We fail to see why PPI Forums should be abolished rather than being enabled and encouraged to evolve in partnership with the voluntary sector. Such disruption is very disheartening to the volunteers who have invested considerable time and effort into the PPI Forums.

We consider that some of the key features of PPI Forums that have enabled us to work productively are not being replicated in the proposal for Local Involvement Networks which is likely to prove very detrimental to the working of LINks.

Finally we have not been convinced that the structure of LINks, with perhaps hundreds of members, has been thought through to produce an effective operation that has to cover Social Care as well as Health.

1. Purpose of patient and public involvement

1.1 To ensure that NHS Trusts are always giving priority to the needs of Patients and the public in all their decisions and service delivery

1.2 To ensure monitoring of the provision of services from the Patients’ viewpoint to check that the stated policies of Trusts are being fully carried out on the ground.

2. Form of patient and public involvement that is Desirable, Practical and Offers Good Value for Money

2.1 Needs to be able to attract capable volunteers from various backgrounds representative of the community and give them a structure within which they can feel that they are making a useful contribution to society.

2.2 The structure must allow the volunteers to be independent of the NHS and of Local Authorities. If not independent of the NHS then there will be undue pressures to conform to the NHS professionals. We see a difference between democratic accountability of the NHS which is secured by Local Authority Overview and Scrutiny Committees and the view of concerned groups and individuals which has been provided by PPI Forums.

2.3 The structure must provide for the adequate oversight of all parts of the NHS. In particular there need to be separate groups to review and monitor the PCT services, and for each Acute and Mental Health and Ambulance Trust with which the PCT has major commissioning arrangements (if necessary jointly with other commissioning PCT(s)) and for Social Care.

2.4 There needs to be a supporting structure for the volunteers. In our area the Forum Support Organisation (The Carers Federation) has provided administrative services and this has worked well. But we have lacked policy and research support which has reduced our effectiveness.

2.5 There needs to be a national organisation to spread good practice and express the views of Forums on the national scene. The Commission, CPPIH, has not been a vehicle for the views of Forums. In the discussions leading up to Government’s present proposals CPPIH were advocating positions expressly antagonistic to the views of most Forums.

2.6 The PPIF system of volunteers must be seen to be complementary to the duty of NHS Trusts to undertake their own PPI activities.

3. Why are existing systems for patient and public involvement being reformed after only three years?

3.1 We wish we knew! Especially as the system is not being reformed, it is being re formed. The reduction in the number of PCTs has already reduced the number of Forums and Forums are at a stage where development has become possible.

3.2 Perhaps the desire to abolish quangos, which resulted in the statement that CPPIH would be abolished, meant that something had to be done. Situating the PPI in Local Authorities was the easy answer for cash distribution but the ethos of Forums would not sit there easily. The option of establishing a Community Interest Company to distribute grants and to monitor Forums should have been explored.

3.3 Perhaps we were being too successful for some people.

3.4 Perhaps Forum resistance to earlier proposals to abolish the Forums for Specialist Trusts, which all Forum members see as essential, triggered the decision.
4. How should LINks be designed

4.1 NOT based with Local Authorities.

4.2 If LINks are covering Social Care as well as Health Care then the Health Care arm of LINks should be separate, and satisfy the following conditions, though working co-operatively with the Social Care arm.

4.3 WITH guaranteed powers of inspection. The Bill does not enshrine powers of inspection, it only allows the Secretary of State to give powers by Regulation.

4.4 NOT just for PCTs but for specialist Trusts as well. If LINks are only established for PCT areas then each LINK needs to have separate groups specialising in the PCT and in each Acute and Mental Health and Ambulance Trust that the PCT is heavily involved with. The Groups involved with the Acute and Mental Health Trusts should be joint ones with involvement of the LINks of all appropriate PCTs.

4.5 Foundation Trusts MUST be within the system.

4.6 WITH guaranteed involvement of all Forum members who are willing including Forum Members from Specialist Trusts.

4.7 NOT performance managed by Local Authorities. LINks should not become subservient to OSCs.

4.8 NOT financially controlled by Local Authorities. If funding is through Local Authorities then it should be ring-fenced.

4.9 There should be a national code of practice for the operation of LINks.

4.10 HAVE adequate finance for administration, for promotion, for consultation and for research.

4.11 CONTINUE the work of Forums, rather than starting again as Forums did after the abolition of Community Health Councils.

Leicester City PPI Forum
Leicestershire County and Rutland PPI Forum
The Leicestershire Partnership PPI Forum
and
The University Hospitals of Leicester PPI Forum

9 January 2007

Evidence submitted by the Local Government Association (PPI 108)

LGA KEY POINTS

— We support the principle of the LINks scheme and the model proposed;
— Effective community networks can reduce health inequalities and increase community cohesion;
— All health and social care agencies must be under a duty to cooperate not only with LINks and scrutiny committees, but with Local Area Agreement partners as well;
— The relationship between LINks and scrutiny committees must be clarified to ensure that work programmes are not duplicated.

ABOUT THE LGA

1. The Local Government Association (LGA) speaks for nearly 500 local authorities in England and Wales that spend some £78 billion pounds per annum and represent over 50 million people. The LGA exists to promote better local government. We aim to put local councils at the heart of the drive to improve public services and to work with government to ensure that the policy, legislative and financial context in which they operate, supports that objective. We would be pleased to give oral evidence to the Committee.

INTRODUCTION

2. One of the LGA’s ambitions for the people and places we represent is to give people greater power and influence over their lives, their services and the future of the places where they live. The challenges we face as a society place a premium on a local response to local circumstances, and the development of local solutions and local choice. It is at the local level, where services are delivered, that individuals have the knowledge and opportunities to make choices for themselves, and where they can, if they wish, play a part in the political process of making choices and shaping and determining public services in their area.
What is the purpose of patient and public involvement?

3. Responsiveness to local people means giving people the power to drive service improvement and value for money and hold all local public service leaders to account for their performance. The creation and fostering of active citizens’ groups, voluntary and community organisations, and social enterprise is key to improving services, reducing health inequalities and building strong communities. Local councils are committed to the ethos of community development, regarding participatory democracy not as a threat to or substitute for, but a vital complement to representative democracy. We are concerned however that the Government’s expectation of wide and deep community involvement in LINks is unrealistic without adequate support and training, particularly when dealing with specialist areas of medicine. In rural areas LINk members could incur significant costs to travel to meetings. These factors could lead to LINks being dominated by narrow, single issue groups, one of the criticisms of PPI Forums.

4. The LGA recommends that:
   - expenses for LINks members are considered;
   - adequate resources to train and support both individual and community capacity for patient and public involvement are made available;
   - host organisations are required to ensure as broad community representation as possible.

What form of patient and public involvement is desirable, practical and offers good value for money?

5. The LGA supports the development of LINks, as set out in the Local Government and Public Involvement in Health Bill (the Bill), and the abolition of PPI Forums, as part of the move towards greater transparency and the integration of health and social care services. Accountability and sensitivity to local people has long been missing from the patient journey, which is becoming ever more complex in terms of the number of providers and different funding methods. There is also an increased focus on wellbeing in Local Area Agreements (LAAs). We are concerned that the main focus of LINks is expected to be the PCT, as the commissioning organisation, without sufficient emphasis on the performance of individual contractors such as NHS Trusts, Foundation Trusts and GPs.

6. It is right that host organisations and LINks will be independent of councils and health bodies. Locally-focused and locally-derived bodies, without prescribed structures, have the potential to provide the best avenue for local people’s involvement at all stages of the commissioning cycle—strategic needs assessment, service planning, contracting and monitoring. The power to visit premises and ask for information will also support local people’s input to the regulatory process. However, councils are increasingly devolving service provision externally, eg to voluntary and community organisations through “compacts”, and we are keen to release the potential of these organisations to develop social enterprises and build social capital. We would not want any blurring of roles between provider, LINk host or LINk member within any single organisation to damage community confidence in LINks.

7. The LGA recommends that:
   - the experience and knowledge of PPI Forums is not lost and that the transitional provisions ensure that knowledge is captured;
   - the potential role of service providers as hosts or members of LINks be clarified to prevent conflicts of interest;
   - all health and social care agencies must be under a duty to cooperate not only with LINks and scrutiny committees, but with Local Area Agreement partners as well; and
   - in the context of an increasing number of people purchasing services for themselves, LINks be given guidance on how to involve individual budget holders and those in receipt of direct payments.

The relationship with council Overview and Scrutiny Committees (OSCs)

8. LINks will be able to refer health and social care matters affecting their area to an overview and scrutiny committee (OSC). The Bill allows for external scrutiny of council social care services by patients and the public (via LINks) for the first time. The scope of scrutiny is explicitly extended to cover the activities of partners contributing to the development or delivery of Local Area Agreements and scrutiny committees will be given powers to require evidence from such partners and to require them to respond to scrutiny recommendations. We support these proposals.

9. However, we want to be sure that the proposals in the Bill do not undermine LINks or compromise the health scrutiny role of councils, and that the enhanced powers of OSCs (to call partners to give evidence, and the duty on partners to respond to scrutiny recommendations) extend fully to health matters. If we are to integrate health and social care provision to improve patient outcomes and reduce health inequalities then all health contractors, including NHS Trusts and NHS Foundation Trusts, should be named as LAA partners and fall within the extended scope of OSCs. We do not believe that the community elements of NHS Trust and Foundation Trust governance arrangements are a substitute for independent local scrutiny.
10. Additionally, practise based commissioning (PbC) allows for social care commissioning by GPs yet it is not clear how concerns LINks may have about GP commissioned social care, including charges and eligibility criteria, would be dealt with by OSCs.

11. The LGA recommends that:
   — the enhanced powers of OSCs apply to all health bodies;
   — concerns about social care commissioned by GPs can be referred to OSCs by LINks; and
   — in order to make best use of resources, the work programmes of LINks and OSCs are co-ordinated to prevent duplication or omissions.

National co-ordination of LINks

12. It is crucial that these new organisations can share information, research and good practice increase their effectiveness and to reduce overall costs.

13. The LGA recommends that:
   — a central website, through which all LINks can communicate with each other, is established, most sensibly by the recently established NHS Centre for Involvement.

Accountability of the LINk

14. As with any organisation there is potential for it not to carry out its functions properly. At present there appears to be no robust mechanism for performance management or for managing a situation in which a LINk has become dysfunctional other than to enforce the contract with the host organisation.

15. The LGA recommends that:
   — scrutiny committees have the power to scrutinise the performance of LINks, perhaps when the LINk publishes its annual report; and
   — scrutiny committees have the power to scrutinise the operations of LINks should organisational dysfunction occur, possibly through a referral from the host organisation.

A specification and budget for LINks

16. DH proposes to publish a model specification for LINks for council procurement officers. Currently £28 million is spent on the Commission for Patient and Public Involvement in Health (CPPIH), forum support organisations and Patients’ Forums. Although LINks will be fewer in number than Patients’ Forums it is possible that the wider remit of LINks and the need reach out to the full diversity of communities will increase costs, however the amount of money to be provided to councils to carry out this new duty has yet to be confirmed.

17. The LGA recommends that:
   — the relative roles of the host organisation and the LINk itself be well defined in the model specification; and
   — the budget provided by DH to councils must cover the costs to the council of procurement and contract monitoring, as well as the running costs of the host and LINk.

Strengthening section 11 of the Health and Social Care Act 2001

18. The Bill strengthens the provisions of section 11 of the Health and Social Care Act 2001 (as amended) by placing a new duty on NHS bodies to consult service users (or their representatives) about proposals that would have a substantial impact on the manner in which services are delivered or the range of health services available as experienced by the user. Primary Care Trusts will now be required to give information on consultations it has carried out before making commissioning decisions and how influential the results of the consultation were on those decisions.

19. Several OSCs have referred “substantial” changes in healthcare to the Secretary of State yet the process that the Department goes through to determine whether such referrals are upheld or rejected, and the criteria used to assess whether the Independent Reconfiguration Panel is asked to provide advice, is not publicly available. OSCs, and in future LINks, would certainly find such information helpful.

20. The LGA recommends that:
   — the Department for Health publishes its process for determining referrals from OSCs, perhaps in collaboration with the Centre for Public Scrutiny.

Local Government Association

January 2007
THE PURPOSE OF PATIENT AND PUBLIC INVOLVEMENT

1. The purpose of patient and public involvement is to give the views of patients and the public to the NHS at every level from Government down to practices. Whilst every institution in the NHS can give an individual view unified by its board or Chief Executive, patients’ views are diverse, even on the same subject. For example, there is no one mode of birth which would be chosen by all women or even by one woman on all occasions. Yet there are professional tendencies towards simplicity, cost efficiencies, experimentation or conservatism which may not be readily reconciled with the patient’s interest.

“PATIENTS” AND “PUBLIC”

2. It is incidentally the case that we see no clear distinction between patients and the public. Failed asylum seekers are not patients in quite the same senses as others though obviously they may become patients in reality. Private patients are not public patients but may become so. Parliament named “Patients’ Forums” by Act of Parliament36 but it also named the “Commission for Patient & Public Involvement in Health” in the same Act and that body prefers to ignore the Act when describing Patients’ Forums. It describes them as “PPI Forums” (without expanding the abbreviation, so obscuring its meaning to the public at large and even to some forum members, for whom they have recently included the acronym in a glossary). In any recommendation the Committee may make, we trust that they will use the shortest and clearest descriptions.

DESIRABLE FORM OF INVOLVEMENT

3. We are in no doubt that independent, unpaid volunteers are the ideal source of patients’ views but this is sometimes difficult to achieve. The whole culture of the country has changed since the days when all public service on local councils was unpaid. There are fewer people willing to work for nothing.

4. Yet we believe that the unpaid volunteer has more to offer than some who are paid. The former Community Health Councils (seemingly retained in part of the United Kingdom) consisted predominantly of unpaid appointees of local councils and unpaid (though sometimes paid) representatives of voluntary organisations, very like the proposed LINks. We believe that paid employees of voluntary organisations have too much vested interest and should not be allowed to serve on LINks management committees which they will often wish to address on behalf of their organisation. There should also, of course, be public declarations of interest, not merely financial interest. Nothing about this is as yet in the Local Government and Public Involvement in Health Bill currently before Parliament.

THE CASE FOR REFORM

5. The Committee asks why further reform is necessary only three years after Community Health Councils were abolished. It is for the Committee, not us, to determine why Ministers and civil servants decided to abolish Community Health Councils in England. The absence of any original proposal to replace them leads us to believe that the Government took the view that any non-NHS view of the NHS was inconvenient, the view of bureaucracies throughout the ages. We find the actions of the Members of Parliament who forced an alternative form of patient participation on the Government very praiseworthy.

6. Unfortunately, since the Community Health Councils had been abolished, the Patients’ Forums had to be set up by someone. The Government chose to set up a new quango (quasi-autonomous national government organisation) to do this. In our view this was a considerable mistake since the quango, the Commission for Patient and Public Involvement in Health (CPPIH), was itself bureaucratic and not particularly competent. In its first year, it set up 10 offices for itself, employed over 100 staff and yet outsourced its primary duties to various organisations contracted to itself (not to the Patients’ Forums some of them serve) under a contract written without appropriate professional advice on behalf of the taxpayers. It spent all its money and had little to spend on advertising for members of forums or on forums directly by Parliament. The whole culture of the country has changed since the days when all public service on local councils was unpaid. There are fewer people willing to work for nothing.

7. The view of Patients’ Forums, when they came to exist, of the CPPIH was not favourable. Members were appointed in an arbitrary way without consultation with existing forum members. They simply appeared at meetings without any biography or advance warning and, most importantly, their contact details could not be circulated because the CPPIH had not obtained their consent. CPPIH know the contact details, of course, giving rise to the suspicion that they kept them secret to retain power in their own hands.

8. Above all, members can be dropped from forums in an equally arbitrary way. Even the Vice-Chair of a forum could suddenly be excluded without the Chair or any other members being informed by CPPIH. CPPIH habitually informs Forum Support Organisations (FSOs) but not Forums, both of general and particular matters. If Forum members (often professionally qualified in appropriate disciplines) wished to

ascertain whether their FSO was performing under its contract, at least one FSO made allegations against them to CPPIH which were followed by the dismissal of members concerned. There is a system of appeal against dismissal (somewhat revised since CPPIH began) but it has not always been followed.

9. In a well-known case, a member with qualifications and experience which could not be successfully impugned by the FSO was threatened with an action for defamation by an FSO which was “legally” advised by a person who was not a qualified lawyer. It should not be possible for a subordinate organisation to legally threaten the volunteers it supposedly serves in this way.

10. One of our members has kept a list of persons dismissed from forums for doubtful reasons. She has noted that when members are “acquitted” on a dismissal charge the records of the false allegations against them are retained by CPPIH in their records of the members concerned. This is for a substantial period, said to be five years, ie longer than CPPIH has been in existence.

11. We give the above history, not merely because it was requested by the Committee in its terms of reference, but as a guide for the future as to what to avoid. We fully support the Government’s decision to abolish CPPIH. It is worth noting that, in all its unhappy history, CPPIH has never got around to organising information so that every patient leaving an NHS or publicly commissioned private facility is given a Patients’ Forum leaflet stating what such Forums are and what they do (if CPPIH did do this, of course, it would be called a PPI Forum leaflet to obscure the matter). Yet the Commission—which has power to give “advice” to forums—never quite does this. It prefers to give “guidance” and the impression that the forums must follow its will. They must “have regard” to CPPIH advice but that has been known to conflict with other legal requirements when it clearly cannot be regarded as guidance to be followed.

INDEPENDENCE OF LINks

12. We therefore believe that LINks (Local Involvement Networks), to which we have no objection in principle, must not be organised at the top, at national level, by another appointed quango. There should be a national LINk partly elected by regional LINks and partly representing voluntary organisations. We find it incomprehensible that the Baroness Morgan should be consulting voluntary organisations alone and not consulting Patients’ Forums as well. It should also be a requirement of the legislation that Patients’ Forums and all their members should participate in the discussions on setting up LINks and have their membership carried over into the LINk for their PCT area.

NATIONAL CONSULTATION

13. In general, a weakness of present Department of Health consultation is that there is no consultation of Patients’ Forums. The Department has consulted CPPIH but this does not seep through to forums. Other occasional consultees, such as the Patients’ Association, existed before Patients’ Forums but Patients Forums were neveradded to the consultation list when they were created and have, as yet, no national organisation because CPPIH originally saw such a creation as a rival.

14. Had there been national consultation of Patients’ Forums, it is possible that it might have been pointed out to the Department that doctors’ hours of work in a contract should not necessarily be the same as a practice’s hours of opening. As it is, the first sign of the new doctor’s contract to the public was the shortening of practice opening hours.

REGIONAL LINks

15. The Department seemingly agrees that there should be regional LINks. London’s Patients’ Forum Network already exists with meetings of all Forum members in the region and a committee representing different types of trust forum and different areas of London. Other regional forums should be brought into existence as soon as possible, to combine with representatives of voluntary organisations to form regional LINks.

16. Their prime responsibility would, of course, be to relate to Strategic Health Authorities (SHAs) now that the latter nearly conform to standard regions. Though we do not understand why there are 10 SHAs covering the 9 standard regions of England. We support the principle of SHAs conforming to English standard regions.

FINANCE

17. The Government’s proposals to pay local authorities to contract with a host organisation to service a LINk, seem to us to be cumbersome. Since local authority finance should not be broken up into ring-fenced portions, we presume that a minimum standard of service to the LINk will be specified by central government. This needs to be more precise than specifications given to CPPIH. We are fed up with having to sign annually accounts (required by law) which contain no monetary figures whatsoever because CPPIH
does not give forums any money (giving them money is not it seems required by law). The Government should specify that each LINk should have an office in or near the principal offices of the relevant local authority and at least one dedicated staff person.

**Host Organisation**

18. The host organisation’s nature is not, as yet, specified. It needs to be disinterested. A host organisation which is itself a voluntary organisation in the health field would be regarded as biased by others. We could produce at least one example of such a bias actually existing.

19. It should be required that in any dispute between a host organisation and a forum it serves or a member of that forum, there should be independent adjudication, in fairness to both of them. “Independent” in this context should mean independent of the forum, the host organisation or local authority contracted to the host organisation.

20. We are not clear how host organisations are to be chosen. If by each local authority separately, there will be no economies of scale. This is what the Bill seems to cover. Cooperation between authorities to employ the same host cannot be guaranteed and may not always be desirable.

**Statutory Powers of LINks**

21. The statutory powers of LINks should cover approximately those of Patients’ Forums and the former Community Health Councils. Confusion was caused by the initial proposed omission of powers of “entry and inspection”. Anyone who has entered a busy London teaching hospital or even a busy general practice during opening hours, realises that entry is open and free. It is only in certain areas, eg a children’s hospital or ward of particularly vulnerable people inside a larger hospital, that restrictions on entry are necessary.

These lead to Criminal Record Bureau checks which delay appointments but there seems no reason why all Forum or LINks’ members need such checks, as a Government Minister, Rosie Winterton, recently pointed out.

**Entry and “Inspection”**

22. The power of inspection caused even more unnecessary fuss, seemingly because national organisations with inspecting powers objected to others apparently having the same powers. In fact, there is no real similarity between a group of lay patients visiting a ward or other unit and, say, the Healthcare Commission’s professionals inspecting a whole trust. The Healthcare Commission might, however, consider incorporating lay persons in its inspection teams, as OFSTED and Primary Care Trusts do. That Commission should always ensure, whenever it inspects a trust, that the relevant Patients’ Forum or LINk is consulted.

**Relations with Trusts**

23. Relations with local health trusts vary, as is inevitable. With a few trusts it would be helpful to prescribe that a LINk may appoint an observer at trust public board meetings, who might speak at the chair’s discretion. With good trusts this is what happens already. In fact they invite their Patients’ Forum to send a representative to private meetings of sub-committees and steering groups.

24. The relationship with Foundation Trusts is subject to an odd technicality. If the trust deed specifies the Patients’ Forum related to the trust (which exists by law anyway) should have a representative on the Members’ Council, it does. If the deed does not mention it, the Forum, as such, is unrepresented. In either case there are directly elected patients’ representatives but no necessary relationship between them and the Patients’ Forum. This technicality should not be perpetuated in the new LINks. The patients’ representatives should continue to be directly elected but one should be a LINk representative.

**Relationship with Host Organisation**

25. As we have pointed out in paragraphs 7–10 above, relations with FSOs, though usually good, have in exceptional cases been poor. To avoid this in future it is necessary that the relationship and communications between local authority and host should be published as far as their LINk is concerned. As stated in paragraph 19 above, there should be provision for independent adjudication of disputes between LINk and host or LINk and local authority.
RELATIONSHIPS WITH OVERVIEW AND SCRUTINY COMMITTEE

26. In general, Patients’ Forums are dubious about Overview and Scrutiny Committees (which in this context are sometimes Health and Social Care Sub-Committees). There are several reasons for this. The great majority of patients and the public do not belong to any political party and are suspicious of bodies which consist wholly of members of such parties. We could cite examples where control of a local authority has changed resulting in a change of attitudes to health scrutiny. At present there is still a distinction between health (finally taken away from local authorities over 30 years ago) and social care (still a local authority function).

Finally, it would seem that some documents, issued by the Government, confused the duties of local authorities through an elected Mayor or a Cabinet, with those of a Scrutiny Committee or Sub-Committee. The Scrutiny Committee should be required to exercise the authority’s existing power to coopt non-voting members (from in this case the relevant LINKs).

RELATIONSHIP WITH HEALTHCARE COMMISSION

27. The signatory of this evidence chairs the Healthcare Commission’s national forum reference group and there are good relations between the two bodies. The reference group contains two representatives of each of 9 English regions’ patients’ forum members, appointed by CPPIH but in London chosen by the regional network of forums, a practice which ought to be required of all regional LINKs, when they exist. One cannot legislate for good relations, so relationships are best left to such bodies, though we note that—at the time of writing—relations in social care are between local authorities and the relevant inspectorate.

28. Unfortunately, other reference groups either do not exist or are not as effective. For example, the one with the General Medical Council began, had one or two meetings and no more; it has never been formally ended but the GMC has apparently ceased to consult it. The GMC will, of course, have lay members but they are not necessarily connected to any Patients’ Forum or LINK.

29. We trust this answers the questions in the Committee’s terms of reference for its enquiry but, of course, we will readily clarify any point as required.

Michael English
Chair, London Network of NHS Patients’ Forums

8 January 2007

Evidence submitted by Hounslow Primary Care Trust, West Middlesex University Hospital, Ealing Hospital, Ealing Primary Care Trust, Hillingdon Primary Care Trust, Hillingdon Hospitals, West London Mental Health Trust PPI Forum (PPI 141)

A STRONGER LOCAL VOICE

Originally there were Community Health Councils (CHCs). They were made up of 24 members who monitored NHS services in the Borough. 10 members were appointed by the Local Authority, 10 by local voluntary organisations and four by the Secretary of State for Health. Thus they were a fairly representative group of people. Each CHC had a local office often in the high street. CHCs were abolished because they were not sufficiently independent. A Stronger Local Voice proposes to replace PPI Forums with LINKs.

PPI Forums were set up by Act of Parliament and are managed by the Commission for Patient and Public Involvement in Health (CPPIH). The Forums have less powers than the CHCs and they do not help patients with complaints, as this part was passed to another organisation. Now these Forums are beginning to get established they are to be abolished and replaced by LINKs.

A Stronger Local Voice says that LINKs are to be set as follows: “Each local authority with social services responsibilities will be funded to make arrangements for the establishment of a LINK in its area,” and thus the one issue of the CHCs and PPI Forums not being organised by a political organisation are swept under the carpet. Incidentally, this issue was one that every discussion meeting in the consultation period agreed would be a bad thing.

Local authorities and the NHS work together in providing health and social care, so how can Local Authorities be independent; and how much of the funding for the LINKs will be swallowed up by local authority administration costs. The money provided to the local authorities to establish LINKs must be ring fenced for that purpose alone. It appears that appointments onto the LINKs could be at the whim of Local Council Committees.

If the new LINKs do not have the power of access premises providing NHS services, many Trusts will breathe a sigh of relief. Without regular monitoring/inspections the LINKs will not have the information they need to help the Trusts to improve. At this time all Trusts are saving money and having to make cuts or reductions, monitoring visits to see how services are affected at the point of delivery are so important.
Who will be the loser, the patient of course, but the Government says the LINks will have greater opportunity to discuss the issues and with more people. But without any powers LINks will be just talking shops, with no real involvement in improving the patient experience.

LINks need to be supplemented by a regional and national organisation that would allow them to link into the whole community in England. Then LINks could become the organisation that the Government say they want. Even more important they could become the organisation that the Public and Patients want and deserve.

Members feel that if there was a real commitment to patient involvement LINks would be strengthened and better funded.

The Forums' Key Messages to the Government are:

— Ensure that LINks are independent.
— Give the statutory powers the Forums have to LINks
— Strengthen legislation to ensure that LINks have to be consulted.
— Support the LINks by word and deed.
— Support the Public and make a long term commitment to PPI.
— Provide the necessary finance to ensure that PPI can be done.

Geo
VMorgan
West London Inhouse Forum Support Team

January 2007

Evidence submitted by West London Mental Health Trust PPI Forum (PPI 45)

As a committed and growing PPI Forum we welcome the continuation of the chance to continue to input and oversee the debate of mental health provision under the WLMHT. Much has been achieved by our Forum and we are determined to continue our work.

However, under the new proposals, this Forum will be split up by the proposal of LINKs based on borough boundaries. In effect this means that the WLMHT will have three forums (LINKs) to work with, therefore replicating their work three times (possibly not a good use of public funds). Furthermore, we, as a forum, will be split and our support and concern and experience of the WLMHT will be similarly diluted.

As we are all well aware, mental health continues to be stigmatized despite the fact that nearly a third of all workers will suffer from a mental health problem and more incapacity benefit is paid out for mental health problems than back pain.

In order to protect such an important and specialist service we propose that a structure is set up between the three LINKs as a single committee for mental health. This will ensure that vital knowledge is kept within the community to best serve the Trust and its users.

West London Mental Health Trust PPI Forum

8 January 2007

Evidence submitted by LMCA (PPI 126)

1. BACKGROUND

1.1 LMCA is the umbrella body for over 100 national voluntary organisations working to meet the needs of people with long-term health conditions. Our vision is of a society in which people with long-term health conditions have control over their lives and can live them to the full.

1.2 LMCA welcomes the invitation from the Health Select Committee to submit evidence to its inquiry into patient and public involvement (PPI), however is mindful of the tight deadlines for responding which has restricted LMCA’s ability to consult fully with its members. LMCA contacted its members for comment but only received a limited response.

1.3 LMCA will restrict its remarks to those areas relevant to an umbrella body representing voluntary sector patient organisations with an interest in long-term conditions and where LMCA believes it can add value.

1.4 LMCA is aware of the circumstances in which the Health Select Committee is conducting its inquiry. The committee called for evidence at the end of November 2006. The Government has since published legislation to introduce proposals directly relevant to the Health Select Committee’s inquiry on patient and public involvement in the NHS. The health legislation, unusually housed in a local government bill “The
local government and public involvement in health” bill is likely to receive a second reading before the health select committee has had a chance to produce a report. LMCA is concerned that legislation on patient and public involvement may be too far advanced in its legislative stages for the Health Select Committee’s conclusions and recommendations to have any influence on the Government’s proposals within the bill.

2. **What is the purpose of patient and public involvement?**

   2.1 LMCA believes that there must be effective structures and processes for patient and public involvement (PPI) in order to achieve a truly patient-led service. This must be the purpose and aim of any PPI system. LMCA would argue that there is no simple, structural solution to PPI; instead patient voice will need to be embraced at all levels of health and social care, from the planning stage, during the commissioning of services, in the delivery of services and when evaluating the outcomes of health and social care services.

   2.2 The most important “involvement” takes place during interactions between individual, people and professional staff. Partnerships in care and shared decision-making are the most significant changes we can make for patient-centred services. The successful delivery of genuine patient choice (allowing individuals to be fully involved in decisions about how they will be treated) is as important to achieving full patient and public involvement in health and social care as any new system or structure of PPI.

   2.3 The Government has stated that one of the main purposes of the new framework for PPI is to ensure the involvement of local people, including in particular those who are seldom heard. While LMCA fully supports this aim, the Government’s response to “A Stronger Local Voice” shows, to date, that little progress has been made. Of the responses to the consultation on the new proposals for local involvement networks (LINks) only 13% of submissions were received from the voluntary sector and a mere one% from the general public. The majority of responses were received from those already involved in current PPI structures. The new framework, including LINks, has much ground to cover in order to improve the reach of PPI so that it truly reflects the wishes and needs of all patients and the public including seldom heard groups. Engaging such groups will require fresh thinking, new resources and new approaches. It is not clear in the Government’s response to “A stronger local voice” how LINks will be able to achieve further reach where current structures have failed, but we welcome the renewed emphasis on connecting formal mechanisms, such as LINks, to community-based groups.

3. **What form of patient and public involvement is desirable, practical and offers good value for money?**

   3.1 LMCA believes patient and public involvement must be an intrinsic part of public services, with opportunity for involvement at all levels. LMCA supports a system-based approach, such as LINks to ensure that formal channels of patient and public involvement are built into the health and social care structure at a local level. However, in addition to this individual service user involvement will also be achieved through the effective implementation of genuine patient choice and the delivery of accurate, up-to-date and comprehensive patient information.

   3.2 LMCA also believes that there is a need for complementing improvements in involvement at a national level. LMCA is a key supporter of the National Voices project which has been established by a working group of members from the health voluntary sector. The aim of National Voices is to improve engagement with the voices of service users, as represented through the health voluntary sector, in health and social care policy decisions taken at a national level. National Voices would seek to become involved at all stages of policy development, from feeding in initial ideas, commenting on proposals at the earliest possible stage, shaping the design and roll out of new national policy and commenting on existing policy.

4. **Why are existing systems for patient and public involvement being reformed after only three years?**

   4.1 LMCA is not able respond as to why existing systems for patient and public involvement are being reformed again. However, LMCA would welcome a strengthening of PPI in health and social care and can see merits in the new system of LINks proposed in “A stronger local voice” and included in the “Local Government Public Involvement in Health Bill”. In particular LMCA would welcome voluntary sector involvement in shaping local PPI arrangements. In many areas the voluntary sector, including LMCA, members are already engaged in promoting the voice of local service users. Where such expertise exists, LMCA hopes that LINks will be able to build on the voluntary sector’s work rather than duplicate it.

   4.2 It is clear that once current structures have been established, patient and public involvement systems would benefit from a period of stability in order for the system to bed down, form good working relationships with local partners and create a strong identity within its local community.

5. **How should LINks be designed?**

   5.1 LMCA was a member of the Expert Panel established to make recommendations on the future direction of PPI. When the expert panel published its conclusions on 12 May 2006, one of its recommendations was to establish non-statutory bodies to replace patient forums. LMCA notes that proposals in the current legislation create a statutory duty on each local authority to establish a LINk in its
area. There will also be a new statutory duty on service-providers to enable LINks access to certain premises and to require service providers to give information about their services and priorities to LINks as well as respond to any recommendations made by LINks. As such LINks do not have a direct statutory basis, but will be empowered by duties placed elsewhere.

5.2 LMCA supports the flexible nature by which LINKs will be established and recognises that having statutory forces in place will help LINks make NHS and social care bodies accountable to local service users and the public. It is crucial, however, that LINks co-ordinate their requests with other organisations that have a regulatory or scrutiny role so that the burden of requests are not excessive. It is also important to ensure that there is relevant expertise housed in each LINk so that any information or premise search is conducted effectively. Statutory force could help LINks, but PPI will not automatically succeed as a result of statute, as experience has shown.

5.3 Although LMCA supports the proposal that LINks should not be tied to a rigid structure, but instead tailored to suit local needs and requirements, LMCA is keen to ensure that LINks are able to communicate their services and work effectively to patients and the public. PPI has undergone many structural changes in the last few years and as such members of the patient and public are rightly confused as to where or who to turn to, either independently or collectively, in order to raise a matter of concern about their health or social care service.

5.4 The Government’s response to “A stronger local voice” explains that LINks will be a network consisting of many different groups and bodies. It goes on to explain that service users or members of the public may approach LINks through different means—for example via Patients Advice and Liaison (PALS) Officers, through individuals or members of LINks, via websites or comment cards. LMCA’s view is that LINks will have to work hard to establish a clear identity within their communities so that patients and the public are aware of their existence, are aware of the work that they do and are clear about how they can get involved should they wish to.

5.5 LMCA agrees that the work of LINks should cover social care as well as health. Often service users do not distinguish between who it is that is providing their care service. Having a system of patient and public involvement that looks at health and social care as a single entity will help to achieve the provision of seamless services.

5.6 LMCA supports the view that LINKs should be established in a geographical area rather than tied to a specific NHS trust as this will help create a whole systems approach to care. In addition LINks are likely to be more independent of providers and health commissioners because of their status outside of trusts. Independence is key to the success of PPI. LMCA hopes there will be good opportunities both for voluntary organisations to become involved as host organisations or to become involved in LINks.

5.7 LINks need to build on the existing strengths and expertise already held by those involved in PPI under the current structures, as well as benefiting from the perspectives of a wider diversity of people. LINks will need to find innovative ways to reach out to those people who want to get involved but are not yet included. The Government should recognise that this may require additional resources and new ways of publicising and presenting information and opportunities. There is already a body of knowledge about how to engage people, much of this from the voluntary and community sector and outside health. We look forward to the new NHS NCI bringing this together.

5.8 Many people who get involved with PPI will be volunteers. As such LINks should have adequate resources to ensure that volunteers, who are giving up their valuable time, are given the necessary support and training for their needs in order to perform a valuable role within LINks.

5.9 LMCA notes that in the Government’s response to “A stronger local voice” (paragraph 3.0) it is unlikely that there will be separate resources to establish a national organisation for LINks. Rather the Government explains that LINks could use some of their funding to establish a national body should they wish. LMCA believes this is a significant departure from the current structure, where the Commission for Patient and Public Involvement in Health received approximately £9 million annually to support its costs. LMCA is concerned that failing to recognise a cost associated with national co-ordination may result in an overall shortfall of resources for LINks for co-ordinating their work across local authority boundaries and nation-wide. LMCA believes that the Government should resource local authorities with at least an amount equal to the total budget for PPI delivered under the previous (structure in order to secure the successful development of Local Involvement Networks.

6. How should LINks relate to and avoid overlap with other organisations?

6.1 There are a number of bodies involved in PPI. Equally a number of mechanisms already exist through which patients and the public feed in their views, comments and complaints to health and social care organisations. Bodies include local NHS organisations themselves, PALs, local NHS trusts, foundation trust boards and governance structures, Local Authority Overview and Scrutiny Committees, the Healthcare Commission and the newly established NHS National Centre for Involvement. It would be helpful to service users and the public if each body was clear about its remit and functions so that patients,
the public and the NHS itself can identify who to turn to with their particular concern. Likewise LINks will need to build relationships with each of these bodies to avoid duplication of work and to prevent any confusion about who is doing what in each locality.

6.2 LINks must also build on and use existing information available in their locality. For example, large amounts of information is already gathered through patient surveys conducted by the Healthcare Commission, voluntary groups and established organisations and institutes. LINks must be careful not to reinvent the wheel where information or expertise is already available. LINks should complement and build on existing systems—they should not add to confusion by creating alternative structures and systems.

7. In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

7.1 Any organisation which commissions or delivers care services should have at its heart a process for involving and taking into account the views and wishes of its service users. Service users should be involved at the earliest opportunity, in particular when an organisation is considering making changes to the type, level or configuration of services available in a particular area. The establishment of LINks does nothing to dilute this necessity.

8. Further LMCA Comment

8.1 LMCA welcomes LINks as an opportunity to strengthen PPI in health and social care. Without effective PPI, services will never succeed in becoming truly patient-centred. LMCA is optimistic that LINks will offer a good opportunity for voluntary sector participation in PPI.

8.2 LMCA will continue to work with voluntary sector partners to develop National Voices, a networked body of organisations representing the interest of service users in national policy formulation. LMCA does not see National voices as a replacement for CPPIH or for a national voice for LINks.

David Pink, Chief Executive of LMCA was a member of the expert panel whose recommendations were used to inform ministers in the development of the new arrangements for PPI. Copies of the expert panel’s report can also be found at tinyurl.co.uk/jqjg

Sarah Clarke
Policy Director, LMCA

January 2007

Evidence submitted by Macmillan Cancer Support (PPI 111)

EXECUTIVE SUMMARY

— The purpose of patient and public involvement is to improve the patient experience by ensuring that health and social care services are responsive to patients’ needs and wants.

— A variety of methods of patient and public involvement are required to improve the patient experience.

— All forms of patient and public involvement, including informal involvement, must be well-resourced.

— Long-term funding should be provided to fund user involvement facilitators for cancer network partnership groups.

— Users should always be involved in the governance structures of health bodies.

— User involvement needs to be at the heart of the commissioning process and encouraged by inclusion in performance measures, Payment by Results and contracts.

— LINks must be independent of the Department of Health and local authorities.

— LINks should consider the whole of the patient experience.

— Members of LINKs should be compensated for lost earnings and reimbursed travel expenses.

— LINks must be properly funded and resourced.

— The Department of Health should identify where there might be overlap of interest with other LINks.

— LINks should contribute to complaints procedures and processes and lead activities to establish satisfaction with services.

— The development of LINks should be kept under review to ascertain if a lack of statutory powers is hindering the ability of LINks to effect change.
— Overview and Scrutiny Committees should formally ask for evidence from LINks at least twice a year.
— OSCs, trusts, commissioners and regulators should explain how they have worked with LINks in their annual reports.
— The guiding principle of LINks should be that they are user representative bodies.

1. INTRODUCTION

1.1 Macmillan Cancer Support is a UK charity working to improve the lives of people affected by cancer. We provide practical, medical, emotional and financial support and push for better cancer care. A core part of Macmillan’s work is to support and take part in patient and public involvement. By providing funding and support to cancer network partnership groups and self-help and support groups, Macmillan encourages partnerships between users of healthcare services, healthcare professionals and carers to improve healthcare services. We have embedded CancerVOICES, a national network of over 500 cancer service users, into our activities and we also support the national partnership forum that brings together members of all the cancer network partnership groups to influence cancer services.

2. What is the purpose of patient and public involvement?

2.1 Macmillan believes the purpose of patient and public involvement is to improve the patient experience. User involvement can take a variety of forms but should ensure that health and social care services are responsive to patients’ needs and wants. Macmillan uses the term “user involvement” to include patients and carers, any of whom may wish to contribute their views and experiences to improve the patient experience. The Department of Health’s 2004 publication, Patient and Public Involvement in Health, sets out the benefits of patient and public involvement, including increased patient satisfaction, improved relationships with health professionals and influencing NHS policy.37

— The purpose of patient and public involvement is to improve the patient experience by ensuring that health and social care services are responsive to patients’ needs and wants.
— A variety of methods of patient and public involvement are required to improve the patient experience.

Case Study—Patient experience, Arden Cancer Network

A laryngectomy patient had a hospital procedure that required an overnight stay in hospital. After the procedure he was given oxygen and the mask was placed over his nose and mouth. He in turn moved it to his neck and was admonished by nursing staff for doing so. The patient and his carer then worked with the user group, the Laryngectomy Association, and the Royal College of Nursing and Emergency Services to develop a training programme. It has been devised specifically for resuscitation techniques for “neck-breeders” and these training sessions are delivered to emergency service staff including ambulance and fire crews and nursing staff.

Source: Arden Cancer Network Partnership Group End of Grant Report 2006

3. What form of patient and public involvement is desirable, practical and offers good value for money?

3.1 Macmillan supports a range of patient and public involvement methods. User involvement mechanisms should allow for all individuals to have a say in the service they receive personally as well as collectively and must be well-resourced. We believe that all forms of patient and public involvement offer value for money, as involvement mechanisms usually rely on voluntary activity. Costs are incurred, often in the form of a paid facilitator, administration and reimbursement of expenses, but these costs are relatively inexpensive when compared to the service improvements that user involvement achieves.

Case Study—Communication tool, 3 Counties Cancer Network

Patients and carers felt that they did not have enough basic information at the beginning of their journey. User groups, the Cancer Network Partnership Group, Network Site Specific Groups (NSSGs), Clinical Nurse Specialists (CNSs) and Network staff all contributed to the development of a patient information folder, launched in March 2006. It is now given to all newly diagnosed cancer patients in the network, giving pointers to further information, contact details of key staff and sources of support.

Source: 3 Counties Network Partnership Group End of Grant Report 2006

3.2 Methods for involving patients and the public range from one to one involvement in consultations with clinicians to formal local and national user involvement structures, covering both specific disease areas and generic health and social care issues, including Patient and Public Involvement Forums (PPI Forums)

and self-help and support groups. Macmillan has supported the establishment of over 700 self-help and support groups by providing grants and training. Self-management by a patient of their own care is another method of involvement, an example of which is the Chronic Disease Self Management Programme, part of Macmillan’s Living with Cancer project. This programme is run by people who have had a cancer diagnosis for others with a cancer diagnosis and helps participants to get more out of life by action planning and goal setting.

3.3 The Department of Health patient involvement agenda has tended to focus more on formal patient involvement structures, and though the Health Select Committee’s inquiry is focusing primarily on formal methods of involvement, the importance of patient involvement during informal interactions between healthcare professionals and patients should not be forgotten. We believe the culture of the NHS needs to change so that patients are routinely involved in decision making in partnership with clinicians. Healthcare professionals should be provided with appropriate training as part of their core medical training and ongoing professional development, including the provision of advanced communication skills training as required. The wider use of evidence-based decision making tools, “power questions”, and written treatment plans should be explored. Macmillan believes that support and information is also key to facilitating greater patient involvement in decision making. For informal methods of public involvement to work successfully, healthcare professionals need sufficient consultation time with patients, proper support and must understand that listening to and working with patients and the public requires a different relationship, one of listening and facilitation.

3.4 Macmillan, in partnership with the Department of Health, has developed a successful model of user involvement, the Cancer Partnership Project. The project provided pump priming funding over three years for user involvement facilitator posts to support partnership groups in cancer networks. These groups bring together cancer service users and health professionals and are now established in all of the cancer networks in England. Partnership groups consist of around 15 patients and meet on average every month. They are supported by staff, ideally a minimum of a full-time facilitator and part-time administrator but in some networks user involvement is not seen as important and staff resource is significantly and inadequately less.

3.5 The Cancer Partnership group model recognises that users and healthcare professionals have a common interest in working to improve the quality of care and, as such, is a unique and effective approach, signalling a change in the culture of the NHS towards real partnership working. Users are represented on the Network Board and its various sub-committees and also take part in the peer review process through which networks are audited. An independent evaluation of the Cancer Partnership Project showed that partnership groups have brought about tangible improvements in information, communication of bad news, transportation, parking, waiting times and the design of new buildings. The evaluation also found that partnership groups functioned better when supported by a dedicated facilitator rather than a health professional for which facilitation was a secondary role. However, since the project funding has stopped, some of the groups have struggled to secure sufficient long-term NHS funding. Macmillan believes it is essential that long-term funding is provided to enable user involvement facilitators to continue to develop partnership groups.

Case Study—Communication of significant news, North East London Cancer Network

The effective communication of significant news was identified as a key area in supporting cancer patients and carers when they are given sensitive, life changing information concerning their health and wellbeing. The Patient Partnership Group provided positive and negative experiences of the communication of significant news, along with examples of policies and a protocol that health professionals can follow. A cancer service user representative took the evidence to the Palliative Care Advisory Board and this led to the development of a resource to support the communication of significant news between patients, carers and health professionals. The Palliative Care Advisory Board are hoping to develop a Network wide policy on the communication of significant news in the near future.


3.6 The Government needs to ensure that user involvement is embedded into the commissioning and provision of health and social care services, so that the patient voice is at the heart of service improvements. Macmillan believes users should always be involved in the governance structures of health bodies, to ensure the patient voice is heard at strategic and operational levels of organisations. Measures for encouraging user involvement should be introduced into performance measures and could be included in reward mechanisms such as Payment by Results, perhaps through the development a QOF-style system of quality indicators.

3.7 Macmillan also believes that users must be involved in the commissioning process. The user voice is currently not well represented in the commissioning of services yet in the new NHS environment there will be more emphasis on better commissioning. Local Involvement Networks (LINks) could bring together

38 Developed by Stanford University in the USA, and through the Long Term Medical Conditions Alliance and the Expert Patients Programme in the UK.
39 Power questions are designed to empower patients by asking the right questions of their clinicians during consultations.
users to contribute to commissioning decisions, for example, in priority setting, ensuring that non-NHS providers comply with their contracts and ensuring that local services reflect the needs of the local population. A requirement to consult and involve users should be a condition of funding for all providers supplying the NHS and should be included in the Commissioning Framework and the NHS model contract. Introducing such measures would ensure that all providers, including private providers, consult and involve users routinely.

Recommendations

— All forms of patient and public involvement, including informal involvement, must be well-resourced.
— Long-term funding should be provided to fund user involvement facilitators for cancer network partnership groups.
— Users should always be involved in the governance structures of health bodies.
— User involvement needs to be at the heart of the commissioning process and encouraged by inclusion in performance measures, Payment by Results and contracts.

4. How should LINks be designed?

4.1 LINks will be a new formal method of user involvement, replacing PPI Forums. Macmillan welcomes the fact that LINks will build on existing user involvement bodies rather than inventing new structures. LINks should play a role in building the capacity of existing user involvement structures to ensure the user voice influences the development of health and social care services.

4.2 LINks offer the opportunity of bringing together users and user organisations to engage in discussion and debate across the whole spectrum of local health and social care services and to hold local services to account to effect change. If LINks simply run box-ticking, paper based consultations then this opportunity will be lost. Patients and the public with an interest in health or social care or of specific areas should come together to focus on general issues through LINks and identify common areas of work informed by their own experiences.

4.3 Remit and level of independence

4.3.1 It is imperative that LINks are independent of the Department of Health and of local authorities and are free to consider all aspects of health and social care. The geographical remit of LINks will allow members to scrutinise the whole patient journey, from primary and social care, through to secondary care, including both NHS and private providers, to hospices and nursing homes. In this respect, LINks will have an advantage over PPI Forums, which were attached to individual trusts. With the introduction of choice in health care, and where users are given more control over their own social care provision through personal budgets, it will be important that LINks take a wholly encompassing view of health and social care, and use their user perspective to hold providers and commissioners to account across the full range of health and social care services.

Recommendations

— LINks must be independent of the Department of Health and local authorities.
— LINks should consider the whole of the patient experience.

4.4 Membership and appointments

4.4.1 LINks will bring together the public, patients, users and organisations representing patients or users, resulting in a wider membership base than PPI Forums. One of the problems of PPI Forums is that they have a small membership which is not always representative of the local population. The Government has said that members of LINks may choose to appoint or elect a panel or board to represent them and make decisions.41 PPI Forum members were initially appointed by the Commission for Patient and Public Involvement in Health and now this function is conducted by the Appointments Commission; the potentially wider membership base of LINks offers an opportunity for an individual LINk to make decisions about its own governance and membership structures, which is welcome.

4.4.2 To encourage wide-ranging representation and encourage participation, Macmillan recommends that members of LINks are compensated for lost earnings and reimbursed travel expenses. LINks should also encourage user involvement within local organisations, by providing training and sharing best practice and provide advice and support to the local community on how to access health and social care complaints systems.

Recommendation

— Members of LINKs should be compensated for lost earnings and reimbursed travel expenses.

4.5 Funding and support

4.5.1 If LINKs are to be successful, they must be sufficiently funded so they can effectively bring together users and user groups within their geographical remits. Details of the funding formula for LINKs are yet to be announced. The ability of LINKs to engage effectively with local users and user groups will depend heavily on the skills and resources of host organisations, though the Department of Health will issue guidelines on the standards of service and a model contract.42

4.5.2 We believe that LINKs would require at least the same amount of staff resource as PPI Forums. PPI Forums are usually supported by two to three full time equivalent employees. Administrative costs of LINKs are likely to be higher than those of PPI Forums as the host organisation will be servicing a larger membership. There are around 550 user organisations for cancer patients in England, all of which would be eligible to join their local LINK and there will be many more organisations supporting other users throughout the country, plus individuals representing their community who would be eligible to join.43

4.5.3 Local authorities will hold the budget for LINKs and issue the contract for local host organisations to support LINKs. There is a danger that this will mean that the independence of the host organisation may be compromised. Local authorities must ensure that tendering procedures for awarding contracts to host organisations are transparent and independent.

Recommendation

— LINKs must be properly funded and resourced.

4.6 Areas of focus; Relations with local trusts; Complaints

4.6.1 A LINK will be established for each local authority with a social services remit, whereas PPI Forums are currently established for individual trusts. As LINKs will be set up for each local authority with a social care remit, LINKs may overlap with each other, particularly if they set up sub-groups to scrutinise hospital trusts or other services, as trusts are not fully coterminous with local authorities. Coupled with the introduction of choice in healthcare, which means that patients may travel further afield for care, it is likely that not all the users of a particular health and social care service will belong to the same LINK. LINKs will need to work closely together and each LINK will have to decide how far its remit stretches. The Department of Health should identify where there might be overlap of interests.

4.6.2 In a 2005 report, the Health Ombudsman noted that the NHS complaints system is not centered on patients’ needs. The report also noted that a significant number of complaints cut across more than one NHS organisation, which means that LINKs may be better able to effect change due to complaints, as they will have a wide geographical remit.44 The report also noted that there was potential to involve Patients Advice and Liaison Services, Independent Complaints Advisory Services and PPI Forums in reviewing complaint procedures and we recommend that LINKs takes a role in scrutinising the complaints procedures of trusts. LINKs should work closely with PALS and ICAS and should be notified if there is a recurring pattern of complaints. LINKs should also take the lead in conducting consultations and gathering information to establish satisfaction with health and social care provision.

Recommendations

— The Department of Health should identify where there might be overlap of interest with other LINKs.

— LINKs should contribute to complaints procedures and processes and lead activities to establish satisfaction with services.

43 NICE, Improving Supportive and Palliative Care for Adults with Cancer, 2004.
4.7 Statutory powers; Overlap with other bodies

4.7.1 It is disappointing that LINks will not have statutory powers. We recommend that the establishment of LINks is kept under review, in particular to see whether a lack of statutory powers hampers the activities of LINks. If LINks are to bring together patients and the public to improve the patient experience, then they must have the ear of trusts, commissioners, providers, and regulators so that users' views are heard and acted upon. A review of the LINks pilot sites should also be conducted to identify whether a lack of statutory powers is hindering activity.

4.7.2 As LINks will not have statutory powers, it will be essential that LINks and Overview and Scrutiny Committees (OSCs) work closely together, so that LINks are effecting change through the statutory powers of the OSCs. We recommend that OSCs formally ask for evidence from LINks at least twice a year.

4.7.3 LINks will also need to work closely with regulators to coordinate inspections and share findings. The Healthcare Commission and other regulators should seek the views of LINks when conducting annual checks and specific investigations. It might also be appropriate for LINks to provide regulators with reports or alert regulators to possible bad practice. LINks must form positive working relationships with the Boards of Governors and Directors and members of local Foundation Trusts; Foundation Trust members could join LINks. We recommend that OSCs, trusts, commissioners and regulators include details of how they have worked with LINks in their annual reports.

4.7.4 In the Government’s response to “A Stronger Local Voice”, it states that a Visiting Code of Conduct will set out guidance for LINks that wish to conduct visits and that inspectors or visitors of health and/or social care services should have the “right” skills and training. It is important that sufficient funds are provided for such training. The Code is yet to be published but Macmillan believe that the “rights” it will contain should not preclude the majority of LINk members from conducting visits or require users to undertake extensive training. The guiding principle of LINks should be that they are user representative bodies and they should not require their members to become semi-professional in order to participate in some of their activities. We would urge the Department of Health to consult on the Code.

Recommendations

— The development of LINks should be kept under review to ascertain if a lack of statutory powers is hindering the ability of LINks to effect change.
— Overview and Scrutiny Committees should formally ask for evidence from LINks at least twice a year.
— OSCs, trusts, commissioners and regulators should explain how they have worked with LINks in their annual reports.
— The guiding principle of LINks should be that they are user representative bodies.

4.8 National coordination

4.8.1 Effective coordination at a regional and national level will be essential if LINks are to represent users and achieve change across social services and the NHS; users will inevitably have concerns or views that are replicated regionally or nationally. Macmillan has been involved in the development of proposals for “National Voices”, an umbrella body bringing together national organisations representing users. It is not yet clear whether “National Voices” will be established, nor is it clear how LINks would interact with “National Voices” once LINks are established. We hope that LINks and “National Voices” would work closely together.

5. In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

5.1 Section 11 confers on each Strategic Health Authority, Primary Care Trust and NHS trust a statutory duty to make arrangements with the aim of involving patients and the public in the planning and decision making processes of that body, if changes will affect the operation of the health services for which the body is responsible. In relation to Health Authorities, this covers both the hospital and community health services for which they are responsible and the family health services provided by practitioners in their area.

5.2 Consultation should be conducted through a variety of channels, including public meetings, speaking to local user groups, surveys, polls and so on. Circumstances where consultation should occur include significant changes to local services such as relocating or closing a unit but it would also be appropriate to consult on the detail of service provision, for example, car parking charges at the local hospital.
6. CONCLUSION

6.1 Well-resourced patient and public involvement mechanisms can bring about real changes in NHS services. The Government, providers and commissioners must embed patient and public involvement at all levels of the NHS and involvement must not be tokenistic. Macmillan broadly supports the proposals for LINks. However, their success will be dependant upon funding, the skills of the host organisation and the ability of LINks to bring together users within a local community and coordinate activity regionally and nationally. Governance and funding arrangements have yet to be made public. We recommend that the Health Select Committee conducts a follow-up inquiry into the operation of LINks once they are fully operational. LINks must be independent, have the interests of all users at their heart and establish effective working partnerships and dialogue with Overview and Scrutiny Committees, local health and social care services and regulators.

Laura Thomas
Macmillan Cancer Support
January 2007

Evidence submitted by Macmillan Patient and Public Involvement, Central South Coast Cancer Network (PPI 56)

1. EXECUTIVE SUMMARY

There is a need to clarify for patients, carers and “citizens” the nature and value of involvement. This would benefit from identification of the two strands of involvement—ground level, including day to day interface and participation in decision making and treatment and care choices, to the broad level of involvement, involving partnership approaches to generate policy and organisational service improvement and change.

There needs to be increased commitment and structure to facilitate ground level engagement, which will involve training and education of health care workers. For broad involvement, patients/citizens need to be able to see the results of their efforts; this will require robust links, resource and skilled facilitation to achieve and maintain.

2. INTRODUCTION

The concept of Patient and Public Involvement is firmly embedded in the structure and organisation of the Central South Coast Cancer Network where I am employed as a Lead to facilitate this function. A nurse by profession, I have 20 years experience within the acute health sector, in both practice development and clinical nurse specialist roles. This, coupled with my current role has enabled me to develop a realistic overview of the patient and public involvement agenda in health, both at the ground level and broader, strategic level.

3. THE PURPOSE OF PATIENT AND PUBLIC INVOLVEMENT

Many patients and their carers remain unclear as to the nature of “involvement”. It would be helpful if there was recognised, clear definition around the levels of involvement, to identify:

(a) ground level patient involvement in day to day clinical and social treatment decisions and choices; and

(b) broad involvement and feedback approaches including membership of forums/LINks, etc and generation of policy and organisational change.

4. What form of patient and public involvement is desirable, practical and offers best value for money?

(a) Ground level: In daily clinical practice, patients report that their feedback to practitioners goes unrecorded- if there was a clear mechanism for these opinions to be captured at the time, published and responded to, themes may emerge which would inform the need for change. This would offer the best value for money, by reducing the need for resource intensive surveys and one-off events. It would also ensure that themes for improvement were increasingly service user driven. For example, many oncology patients describe lengthy waits in clinics, but their suggestions of how this process could be managed more effectively can currently go unheeded.

(b) Broad involvement: In our experience, patients and their carers describe that they are keen to be involved at a local level, where they can see the benefits and changes that occur as a result of their actions or feedback. Many patients have difficulty in travelling, or prefer to work at a local level. By increasing the geographical area, and clinical patient flow routes served from PCT’s to Local
Authority boundaries, this may actually deter patients from attending or being enthusiastic about becoming members of LINks. From the perspective of cancer patients, one local authority may encompass a number of health providers and commissioners.

The new LINk scheme may disadvantage the involvement of those with an interest in health, as the inherent social care remit would be anticipated to be stronger and more highly represented. Recruitment of patients to LINks is likely to be even more complex than is currently experienced, as it may be difficult for people to see the relevance and how they link back successfully to health care provision.

5. RECOMMENDATIONS FOR ACTION

(a) Ground level involvement: Increase the profile for patient and public involvement, choice and joint decision-making to patients through advertising, and ensuring that this is embedded through education, training and the knowledge skills framework as an essential part of all health service roles. Ensuring that it forms part of objective organisational work plans and outcomes, as in the Cancer Measures (2004) will lead to greater awareness and commitment from health professionals. Another option would be the development of NHS health trust “Patient Involvement Champions” to raise the profile, facilitate and implement projects and promote organisational focus.

(b) Broad Involvement: Ensure that there are robust accountability, governance and defined communication links and responsibilities to both social care and health providers and commissioners. This will enable patients/citizens to see demonstrable service improvements and changes as a result of their influence and involvement, which is essential to maintain engagement.

One of the main complaints from patients currently involved is that this is the missing link- there needs to be a strengthening of the feedback system to people who have participated and offered their time and effort to express their views and ideas.

Appropriate funding to ensure quality facilitation, training and development opportunities and administrative support to all members of LINks is essential and should be ring fenced, as in times of financial pressure can be seen as a soft target.

Wendy Keating
Macmillan Patient and Public Involvement Lead
Central South Coast Cancer Network
January 2007

Evidence submitted by Medway Community Health PPI forum (PPI 53)

CONCERNS ABOUT PROSPECTIVE LEGISLATION SETTING UP LOCAL INVOLVEMENT NETWORKS (LINKS)

The following comments are based on extensive experience of Community Health Councils and Patient and Public Involvement (PPI) Forums.

— PPI Forums, due to the membership selection process, are diverse organisations with memberships drawn from individuals with wide experience, particularly of people from hard to reach groups. PPI Forums in Medway have been highly successful as a result of this, eg work on privacy and dignity, health in the workplace, etc—full information is available.

— LINKs have an inherent potential weakness in that they could easily become a vehicle for well organised pressure groups.

— PPI Forum members are a non-paid independent group of motivated people. If voluntary organisations/pressure groups form the backbone of LINKs past history/experience demonstrates that paid officials take up membership places. This might seem a trivial point but it goes to the heart of public/patient/carer involvement in health and social care.

— The new system of PPI/strengthening local communities policy is fragmented amongst a number of organisations and has the danger being unfocused on NHS issues in particular.

— Experience of Overview and Scrutiny Committees has demonstrated them as ineffective in providing local scrutiny of the NHS and are recognised as such within the Cabinet system operating within local government.

— Putting the funding of LINKs in the hands of local government creates a conflict of interest in many areas, eg OSCs; grant aiding voluntary organisations, etc.

— Need greater clarity about balance between individuals and organisations within LINKs.

David Elkes
Chairman, Medway Community Health PPI Forum
9 January 2007
Executive Summary

1. There are currently 54 NHS foundation trusts which have around 625,000 members drawn from the public, patients and staff. The patient and public members elect the majority of the Board of Governors of each NHS foundation trust.

2. The numbers involved, and the degree of engagement which is taking place, indicate that membership is providing an effective route by which patients and public can engage with their local NHS foundation trust.

3. The governance structure of NHS foundation trusts has brought a new dimension to patient and public involvement in the NHS. The right to elect governors, who have specific powers in relation to the trust, ensures that members have a specific role in the governance structure of an NHS foundation trust. This is a distinct position from other patient and public involvement initiatives in the NHS.

4. The 54 NHS foundation trusts have around 930 patient and public governors. The boards of governors have been working effectively with the boards of directors, for example liaising on appointments of non-executive directors and overseeing the development of strategy. In Monitor’s view it is as yet too early to say whether governors will be able to have the necessary blend of experience, skills and influence to successfully shape the long term strategy of each NHS foundation trust.

5. The number of NHS foundation trusts will grow steadily over the next two years. This will ensure that the membership concept is firmly established in the majority of acute and mental health trusts and, through the planned creation of community foundation trusts, in primary care settings too.

6. Where patient and public involvement initiatives overlap there is potential for confusion as to the different responsibilities of each organisation. It is therefore essential that the development of the new Local Involvement Networks avoids any duplication with the responsibilities of the governors of NHS foundation trusts.

Monitor and NHS Foundation Trusts

7. Monitor’s statutory name is the Independent Regulator of NHS Foundation Trusts. Monitor was established in January 2004 under the Health and Social Care (Community Health and Standards) Act 2003. Monitor’s statutory responsibilities include the authorisation and regulation of NHS foundation trusts. Monitor is independent of the Department of Health. It is accountable to Parliament.

8. NHS foundation trusts are autonomous organisations. They are no longer subject to direction by the Secretary of State for Health, although they must continue to work within the framework of national targets and standards established by the Secretary of State. Their primary purpose must remain the provision of services to the NHS.

9. The Board of Directors of each NHS foundation trust is responsible for strategy and performance. They are accountable to local members through the Board of Governors.

10. There are now 54 NHS foundation trusts, including five mental health trusts. Their annualised total income is around £10.8 billion (based on 2005–06 figures), accounting for over a quarter of acute trust activity in England.

Members and Governors

11. Each NHS foundation trust has public members drawn from their local population and staff members; it may also have patient members. Members can elect representatives to the FT’s Board of Governors. A majority of the governors must be elected by patient and public members. The Board of Governors has a number of statutory powers including:

   — appointing or removing the chair and non-executive directors;
   — approving the appointment of the chief executive;
   — appointing the auditors of the trust; and
   — considering the trust’s annual forward plan.

12. The 54 NHS foundation trusts have around 625,000 members—see table at Annex A. Around 75% of members are from the patient and public constituencies. There are around 930 patient and public governors. A governor profile for a recently authorised NHS foundation trust is shown at Annex B.

13. Membership provides an effective way of engaging with the local community. All NHS foundation trusts are required to take steps to secure membership which is representative of the communities they serve. The plans received for 2006–07 showed NHS foundation trusts undertaking a variety of activities to engage effectively with their members including:

   — Newsletters.
   — Open Days.
— Leaflets and letters to constituency members.
— Targeted letters to local groups or local authorities.
— Seminar and lecture programmes.
— Surveys and questionnaires.
— Membership stands at local events.
— Emails.
— Articles in local media.

The two examples in paragraphs 14 and 15 illustrate the type of engagement that NHS foundation trusts have had with members.

14. Cambridge University Hospitals NHS foundation trust has one of the largest memberships. Governors have taken responsibility for communicating with members with monthly meetings held in local towns and villages. Meetings take place both in afternoons and evenings to make them more accessible to any member wishing to attend. The trust identified that giving the meeting a theme will increase attendance and so the local member meetings have incorporated topical themes such as the role of the modern matron and hospital food.

15. Chesterfield Royal Hospital NHS Foundation Trust consulted public and staff members on new proposals to change visiting hours at the hospital. As part of plans to reduce hospital acquired infection, members were asked if visiting hours should be reduced. In exchange more cleaning would take place on wards and a new visitors’ code would be adopted—including a ban on more than two patients per bedside. Almost 5,000 responses were received (nearly 50% of the membership). Over 96% were in favour of the new code. However the trust was asked to extend afternoon visiting from a proposed one hour, to a two hour slot—to help visitors travelling long distances. The trust agreed to this change. The consultation led to major changes in the way the hospital operates being implemented with total support from staff, patients and local people.

16. Members’ statutory influence over the NHS foundation trusts comes through the election of governors. Participation rates in elections have averaged around 35% within the public constituency.

17. Monitor is satisfied that across all NHS foundation trusts governors have been carrying out their formal roles in an effective manner, making sound appointments to non-executive director posts, appointing auditors rigorously and overseeing the activities of the organisation effectively.

18. There have to date been no significant cases in which governors have come into conflict with boards of directors. This is to be welcome if it indicates that NHS foundation trusts are running themselves effectively. However, it may suggest that governors have not yet sufficiently found their feet. Monitor welcomes the proposal to establish a governors’ forum, to be run by the King’s Fund, which will provide a focus for governors to share information and learning. There will no doubt be challenges and changes ahead for many NHS foundation trusts and governors need to ensure that they are properly engaged in giving oversight to their organisations if local accountability is to have real force.

19. In 2006 Monitor published the NHS Foundation Trust Code of Governance. This sets out a best practice framework for the corporate governance of NHS foundation trusts, drawing on experience from the private and public sector. In consulting on the Code many respondents suggested that Monitor should provide further guidance on the role of governors. At present Monitor has plans to undertake further work in 2007 on the role of governors and will consider whether it would be helpful to issue further best practice advice on the governors’ role.

Monitor

10 January 2007

Annex A

TABLE OF MEMBERSHIP

NHS Foundation Trusts Authorised as at 31 March 2006

<table>
<thead>
<tr>
<th>NHS Foundation Trust</th>
<th>Total Membership as at 31/3/06</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barnsley</td>
<td>12,602</td>
</tr>
<tr>
<td>Basildon and Thurrock</td>
<td>12,069</td>
</tr>
<tr>
<td>Bradford Teaching</td>
<td>4,221</td>
</tr>
<tr>
<td>Cambridge University Hospitals</td>
<td>23,597</td>
</tr>
<tr>
<td>Chesterfield Royal</td>
<td>13,346</td>
</tr>
<tr>
<td>City Hospitals Sunderland</td>
<td>9,129</td>
</tr>
<tr>
<td>Countess of Chester</td>
<td>4,266</td>
</tr>
<tr>
<td>Derby Hospitals</td>
<td>13,994</td>
</tr>
</tbody>
</table>
### NHS foundation trust

<table>
<thead>
<tr>
<th>Name</th>
<th>Total membership as at 31/3/06</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doncaster and Bassetlaw</td>
<td>7,870</td>
</tr>
<tr>
<td>Frimley Park</td>
<td>7,671</td>
</tr>
<tr>
<td>Gateshead Health</td>
<td>11,171</td>
</tr>
<tr>
<td>Gloucestershire Hospitals</td>
<td>14,609</td>
</tr>
<tr>
<td>Guy’s and St Thomas’</td>
<td>13,368</td>
</tr>
<tr>
<td>Harrogate and District</td>
<td>13,557</td>
</tr>
<tr>
<td>Heart of England</td>
<td>51,038</td>
</tr>
<tr>
<td>Homerton University</td>
<td>5,968</td>
</tr>
<tr>
<td>Lancashire Teaching</td>
<td>14,592</td>
</tr>
<tr>
<td>Liverpool Women’s</td>
<td>10,693</td>
</tr>
<tr>
<td>Moorfields</td>
<td>11,487</td>
</tr>
<tr>
<td>Papworth</td>
<td>11,690</td>
</tr>
<tr>
<td>Peterborough</td>
<td>8,523</td>
</tr>
<tr>
<td>Queen Victoria Hospital</td>
<td>13,031</td>
</tr>
<tr>
<td>Royal National Hospital for Rheumatic Diseases</td>
<td>4,612</td>
</tr>
<tr>
<td>Sheffield Teaching</td>
<td>18,168</td>
</tr>
<tr>
<td>South Tyneside</td>
<td>4,963</td>
</tr>
<tr>
<td>Stockport NHS</td>
<td>11,938</td>
</tr>
<tr>
<td>The Rotherham</td>
<td>5,502</td>
</tr>
<tr>
<td>The Royal Bournemouth and Christchurch</td>
<td>14,990</td>
</tr>
<tr>
<td>Royal Devon and Exeter</td>
<td>15,600</td>
</tr>
<tr>
<td>The Royal Marsden</td>
<td>4,893</td>
</tr>
<tr>
<td>University College London Hospitals</td>
<td>10,194</td>
</tr>
<tr>
<td>University Hospital Birmingham</td>
<td>91,961</td>
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<tr>
<td>TOTAL</td>
<td>471,313</td>
</tr>
</tbody>
</table>

### Trusts Authorised in 2006

<table>
<thead>
<tr>
<th>Name</th>
<th>Members</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oxleas</td>
<td>4,056</td>
</tr>
<tr>
<td>South Essex</td>
<td>8,039</td>
</tr>
<tr>
<td>South Staffordshire</td>
<td>5,026</td>
</tr>
<tr>
<td>Royal Berkshire</td>
<td>10,173</td>
</tr>
<tr>
<td>Salisbury</td>
<td>9,209</td>
</tr>
<tr>
<td>Southend</td>
<td>13,200</td>
</tr>
<tr>
<td>Newcastle</td>
<td>8,678</td>
</tr>
<tr>
<td>Yeovil</td>
<td>5,390</td>
</tr>
<tr>
<td>Aintree</td>
<td>6,398</td>
</tr>
<tr>
<td>Calderdale</td>
<td>2,364</td>
</tr>
<tr>
<td>Clatterbridge</td>
<td>4,179</td>
</tr>
<tr>
<td>James Paget</td>
<td>12,965</td>
</tr>
<tr>
<td>Luton &amp; Dunstable</td>
<td>8,336</td>
</tr>
<tr>
<td>Northumbria</td>
<td>11,031</td>
</tr>
<tr>
<td>Salford</td>
<td>8,008</td>
</tr>
<tr>
<td>Sheffield Children</td>
<td>3,274</td>
</tr>
<tr>
<td>Chelsea and West.</td>
<td>10,914</td>
</tr>
<tr>
<td>Tavistock and Port.</td>
<td>2,300</td>
</tr>
<tr>
<td>South Manchester</td>
<td>9,142</td>
</tr>
<tr>
<td>SL and Maudsley</td>
<td>2,361</td>
</tr>
<tr>
<td>North Hampshire</td>
<td>4,037</td>
</tr>
<tr>
<td>Kings</td>
<td>7,407</td>
</tr>
<tr>
<td>Sub-total</td>
<td>156,487</td>
</tr>
<tr>
<td>TOTAL all trusts</td>
<td>627,800</td>
</tr>
</tbody>
</table>

**Notes:**

1. Membership figures for the first 32 NHS foundation trusts are as at 31 March 2006 as reported to Monitor in Annual Plans for 2006–07.

2. For trusts authorised in 2006, membership figures are as at date of authorisation.
GOVERNANCE STRUCTURE

TYPICAL STRUCTURE OF AN NHS FOUNDATION TRUST BOARD OF GOVERNORS

20 patient and public governors

- 3 Area A
- 5 Area B
- 4 Area C
- 2 Area D
- 1 Area E
- 5 Patients’ constituency

12 appointed governors

- 2 PCTs
- 1 University
- 2 Primary care clinicians
- 2 Local authority
- 1 PFI partner
- 1 Chamber of commerce
- 1 PPI forum
- 1 Local regeneration project
- 1 Voluntary sector

7 staff governors

- 1 Medical and dental practitioners
- 2 Nursing and midwifery
- 1 Other clinical staff
- 1 Non-clinical staff
- 1 PFI staff
- 1 Volunteer

Based on constitution of University Hospital of South Manchester NHS Foundation Trust

Evidence submitted by the Moore Adamson Craig Partnership (PPI 39)

EXECUTIVE SUMMARY

Our evidence concentrates on the form a LINks should take and stresses the importance in PPI work of building organisations around the volunteers and not trying to fit the people into structures. The memorandum argues for and outlines the principal provisions of a new form of contract between the LINks and the individuals who come forward to serve on the body.

THE MOORE ADAMSON CRAIG PARTNERSHIP—SPECIALISTS IN PUBLIC AND PATIENT INVOLVEMENT

The M-A-C Partners Valerie Moore, Colin Adamson and Andrew Craig have worked with patient and user representatives for the past five years and were pioneers in training for this role in partnership with the National Consumer Council. We have also evaluated the success of aspects of PPI programmes and been involved in other health-related initiatives such as Governors in Foundation Trusts. Our approach also draws our experience with other consumer representative organisations in the water and rail industries.
M•A•C aims and approach

To enable user representatives and those who manage and support them in their efforts to develop a coherent and effective approach to their work. We help them:

- Define “representation”/“representative”.
- Identify issues and concerns of those represented.
- Identify strengths and weaknesses of their organisations or as individuals.
- Formulate goals and objectives.
- To evaluate their efforts and to recognise success.

PPI in Health: A Legacy of Disappointment

We believe it is very important to make the new PPI systems and processes work well this time round. In the past few years we have seen growing cynicism and in some cases real anger amongst those individuals who have given time and energy to Community Health Councils (CHCs) and Patient and Public Involvement Forums (PPIFs). In many cases this is matched by a weariness amongst even the most forward-looking service providers and commissioners who feel their organisations and their patients and the public have gained little from the shift from CHCs to Patient Forums. Some complain that their work with the public has been hampered and weakened, partly by repeated structural changes but more importantly by the alienation and subsequent disappearance of individuals and organisations with whom they previously had positive working relationships.

Risks of Getting It Wrong Again

The risks of getting it wrong this time are therefore very high. It is not only a question of making good use of public funds. It is also a question of resuscitating good will and developing positive new relationships. Our work over the past five years in the patient and public involvement field has shown us that the public in general and patients in particular are passionately committed to the idea of a publicly provided health service. They are strongly supportive of their local healthcare institutions at every level and the people who work within them. They want to be involved, but only in things which they see as being relevant to them. Where they have something to say they want to be listened to. They know they are really being listened to when they can see that their feedback has had an impact on the things that matter to them.

A Definition of Independence

It is essential that the new LINks bodies are and are seen to be independent of providers and commissioners of services. But they will also need to help their members (whether individuals or organisations) to have the capacity, knowledge and skills to secure real influence. Many of the failures of Public and Patient Involvement Forums were related to inadequate support both in terms of administration and in terms of expert guidance. We would hope that LINks might end up looking not dissimilar to the very best of the old CHCs with an expert and professional staff supporting the membership.

Radical and Innovative Approach to Support Public and Patient Representatives

We feel there is an opportunity for a radical new approach in this contractual area that starts not with the definition of the appropriate institutional relationships but with creating the space and the environment that will nurture and sustain the individual relationships.

As our initial remarks make clear, the people that suffered from the uncertainties and failures of the past were principally the volunteers, those members of the public, patients and carers who took part and responded to invitations to join in. (This is not to ignore the untimely job losses of CHC staff but their status as employed people ensured that they were not left wholly stranded.)

First Priority to Inspire, Attract and Retain

We therefore see the first priority to create the right conditions or contract to re-inspire, attract and retain the new corps of patient and public participants to resuscitate that goodwill and develop those new relationships.

This person-centred LINks contract would address the following issues:

- A right of audience and to be heard and involved.
- Financial and other barriers to involvement.
- The availability of incentives including payment.
- The amount of training to be given to fulfil the role and to use all modern means of communication and association to do so.
— Full technical support in modern communication channels especially low cost communications.
— The availability of professional support at the times it is needed—eg weekend and evenings as well as daytime—a 0900 to 2100h day.
— Support to include access to research studies and the funds and training to commission their own work.
— The ethical and moral basis for the work and a code of expected conduct to be observed by all parties to the contract.
— The basis for appraisal—how often and by whom and to what end?
— The degree of protection from legal action eg libel.
— Accurate statement of the minimum/maximum time to be devoted to this work and the length of any engagement.
— A means whereby volunteers can negotiate different terms of engagement and of reference to suit their (changed).
— To have the power either to dismiss other contractors and service providers or vary their contracts if they not delivering the service demanded.
— The power to move the closure of the LINks if they are not performing and to allow others to bring such a motion so a fresh start can be made. We are not creating institutions that will last for ever—I we are creating means to ends which if they do not deliver, we can close down and try something else.

If a organisation tendering to set up a LINks shows that it can devise a contract along these lines that can be incorporated into the ‘main’ host organisation contract and budget, then it is a serious contender to run a LINk regardless of whether it is a for-profit or not-for-profit organisation.

Valerie Moore, Colin Adamson, Andrew Craig
The Moore Adamson Craig Partnership
5 January 2007

Evidence submitted by the Motor Neurone Disease Association (PPI 55)

1. INTRODUCTION

1.1 The Motor Neurone Disease (MND) Association welcomes the opportunity to submit evidence to the Health Committee’s inquiry into Public and Patient Involvement in the NHS. Representatives from the MND Association have attended a conference on Local Involvement Networks (LINks) and read the consultation document “A Stronger Local Voice” and the Government response to it.

2. PATIENT AND PUBLIC INVOLVEMENT IN THE NHS

2.1 We would like to make the following points on the proposed new set up for patient and public involvement in the NHS:

2.2 It is important to involve individuals as early as possible in the process, extend membership beyond the larger groups and to try to get the harder to reach groups.

2.3 As Patient and Public Involvement Forums (PPIFs) were set up only three years ago, there need to be some quick wins to show that LINks will make a difference where perhaps PPIFs did not. Many people are sceptical about how long LINks are likely to remain in place.

2.4 It is important to raise the profile of LINks through the media and other channels. PPIFs had a low profile outside of the health sector and it is important to address this for LINks. If LINks are to be successful they will have to become more widely known to the general public.

2.5 LINks need to act as the focal point for patient involvement across health and social care. Currently social care and the NHS both have ways of consulting with patients and LINks need to make sure they are not biased towards health or social care and not duplicating work.

2.6 LINks need to be kept free from personal agendas and political interference.

2.7 LINks need to make sure that the host organisation has independence from the local authority, and that the local authority is not exerting undue influence on the host organisation.

2.8 There needs to be consideration as to how LINks will fit into the democratic process by working with local councillors.
3. **About MND and the Association**

3.1 Few disorders are as devastating as MND. It is a rapidly progressing and fatal neurological condition. MND progressively attacks the body removing the ability to walk, talk or feed oneself, but the intellect and senses usually remain intact. There are estimated to be around 5,000 people living with MND in the UK. Half the number of people with the disease die within 14 months of diagnosis.

3.2 The MND Association’s vision is of A World Free of MND and we will fund and promote research to bring about an end to the disease. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.

*Mark Hill*
MND Association

*January 2007*

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**Evidence submitted by the National Cancer Research Institute (PPI 32)**

I enclose a memorandum of evidence for the forthcoming Health Select Committee Inquiry into Patient and Public Involvement in the NHS.

The submission is from the Consumer Liaison Group (CLG) of the NCRI. The CLG is the national patient/public involvement group within cancer research, drawing its members from all across the UK. Our members also have extensive experience of lay involvement in service development, guideline development with NICE, and in other areas of advocacy in the NHS and healthcare, as well as their involvement in cancer research.

The CLG now additionally works within the PPI structures of the UK Clinical Research Collaboration and UK Clinical Research Network. As the longest established patient and public involvement group within UK clinical research it also has strong links with similar groups in the USA and is encouraging the development of a similar approach in Europe through ECPC, the European Cancer Patient Coalition.

**Executive Summary**

1. The National Cancer Research Institute Consumer Liaison Group (CLG) was formed in 2000 and operates as a partner within the NCRI structure, its members taking part as equals at all levels and in all areas of cancer research.

2. The CLG has been evaluated by an independent review panel of international experts and the CLG, NCRI and NCRN (National Cancer Research Network) have been congratulated on its achievements. A development project to create panels in the cancer research networks has also been evaluated.

3. The core theme of the relationship between consumers in cancer research, researchers and clinical professionals, is partnership. We believe that this approach is returning benefits and can be emulated in other areas of healthcare.

1. **What is the purpose of patient and public involvement?**

1.1 Patient and public involvement in research has a clear set of objectives:

   — to make research more relevant to the needs of patients;
   — to help deliver research results faster through better designed studies which accrue patients more quickly; and
   — to provide evidence which enables health services to deliver benefits to patients more effectively.

2. **What form of patient and public involvement is desirable, practical and offers good value for money?**

2.1 The Consumer Liaison Group (CLG) of the National Cancer Research Institute (NCRI) was established in the late 1990s under a prior research structure. It was brought into the NCRI and the National Cancer Research Network (NCRN) following the Cancer Plan in 2000 and its members have successfully worked in partnership with professional researchers since then.

2.2 The CLG is made up of approximately 60 patients, carers and others affected by cancer who work with the NCRI, NCRN, and with individual NCRI partners on:

   — peer review of research proposals (principally through the 23 NCRI Clinical Studies Groups);
   — strategic oversight, development, and priority setting (with NCRI Board, NCRI Strategic Planning Groups and the NCRN Operational Steering Group);
   — award of funding for new research infrastructure, clinical trials and other research studies (through Department of Health, Cancer Research UK, MRC and other funders);
— periodic review of organizations and initiatives in cancer research (with Department of Health and NCRI partners); and
— development of new research initiatives by the NCRI (eg National Prevention Research Initiative, OnCore UK).

2.3 Members of the CLG also work closely with researchers on new clinical studies. Increasingly the questions which these studies are seeking to answer are influenced by patient/consumer input. Patient information is now being written jointly by researchers and patient representatives in many instances.

2.4 The over-riding theme is one of partnership. To achieve that aim managers and researchers have successfully accepted the challenge of working with patients and carers. In their turn patients and carers have undertaken training and accepted responsibilities which reflect the new access which the NCRI/NCRN structures have opened up.

2.5 The success of this partnership was recorded in March 2006 by an international review panel. It commented:

“The CLG was congratulated on the numerous achievements in such a short space of time. The Group had done a difficult job in a changing environment. The Group was not only working collaboratively and moving forward but also working in a complementary way with the research community.”

also

“It was noted that the Group had moved from developing expertise and was now beginning to develop strategy.”

2.6 The CLG is now evolving to fulfill the demands being made on it by the changing structure of cancer research following recent developments. The evaluation of a pilot project to create three network patient/consumer research panels has given some clear guidance on how effective involvement can be developed in the local research networks. The creation of a new network of Experimental Cancer Medicine Centres (through joint funding from Department of Health, the devolved administrations and Cancer Research UK) has created the need to develop similar partnerships in the experimental/translational research community, with some new challenges to be addressed.

2.7 The NCRI CLG represents a model of good practice for patient and public involvement in research which has been recognized by Department of Health. It is a stable base for patient/public involvement in cancer research but it is not standing still. Its past and present success is providing a foundation for further success as the desire for effective involvement is recognized by the whole cancer research community.

2.8 The CLG is now providing a base model for patient and public involvement in the new clinical research structure through UKCRN, UKCRC, NIHR and MRC.

3. How should LINks be designed?

3.1 We believe that the lessons of the CLG’s success are:
— The context of partnership subscribed to by all parties.
— The stability of the single national group.
— The strength of the commitment made by individuals, both professional and patient.
— The professional support for the CLG as it develops an agenda reflecting patient priorities.

3.2 The independent evaluation of the pilot project to create Network Consumer Research Panels demonstrates that an exclusively patient/public group with a wide remit has problems developing momentum, even when facilitated by a professional secretariat. The lesson for these panels (which were not supported by a compulsory requirement for involvement) was not that compulsion was necessary but that effective partnership building strategies generated demand from professionals and researchers for involvement from patients. This created benefits all round. We believe that compulsion at the outset rather than adopting a partnering approach, presents a risk for a patient/consumer group, potentially encouraging confrontation which, even at only a low level, could be disruptive.

3.3 Patients and the public have a vested interest in seeing health services improve and managers have a professional interest in that improvement. By identifying common agendas and expressing purpose through consensus decisions arrived at through open discussion between equals, on those occasions when common purpose is not evident at the outset, we believe the NCRI Consumer Liaison Group demonstrates that partnership works in research. We believe it can work elsewhere.

Roger Wilson
Chair, NCRI Consumer Liaison Group

5 January 2007
REFERENCES

Evidence submitted by the National Pensioners Convention (PPI 25)

What is the purpose of patient and public involvement?

1. As the NHS is becoming increasingly patient led, it is essential that the community and users of the service should be able to make a major contribution in monitoring changes. Their contribution must be effective and produce results and not simply be used to pay lip service to the idea of patient and public involvement. It is also crucial that the effects on patient care of changes in service provision are monitored.

2. Older people may be particularly vulnerable to changes in the services provided, especially where small hospitals and wards for the elderly mentally ill may be closed. It is most important therefore that patients and the public should have real influence on the way that the NHS is managed locally.

What form of patient and public involvement is desirable, practical and offers good value for money?

3. People who have been involved in Patient Forums and the much missed Community Health Councils have a great deal of expertise in monitoring change in the NHS, exposing faults and bringing about improvements. We need a system where those involved in monitoring changes have a right to inspect services used by the public, particularly in primary and secondary care. The system should be properly funded and enable monitors to express their personal views on local health issues, independent of the NHS itself. Voluntary organisations with a wide knowledge of the local community may also provide valuable expertise.

Why are existing systems for patient and public involvement being reformed after only three years?

4. The NPC still finds it difficult to understand why Community Health Councils were abolished and the successor body, the Commission for Patient and Public Involvement in Health, has also had to go.

5. The arms length review of 2004 recommended that patient forums were to be made the cornerstone of the new arrangements enabling patients and the public to influence local health services. Now they, too, are to be closed down. As the CPPIH was set up in January 2003, the decision to abolish it must have been made after little more than a year of operation.

6. The NPC believes that patient forums could have been improved to provide better patient and public involvement, which would have avoided the inevitable disruption of the work of the existing paid and voluntary staff. Older people in particular simply do not know how they can have an impact on local health services, either when service changes are proposed or when they become aware of faults in the present system.

7. We note that there will be no early end to this uncertainty, when the proposed new arrangements will receive the necessary legislation only when Parliamentary time allows.

8. The NPC’s panel of expert health advisers would be available to give further detailed oral evidence to the committee should they wish.

National Pensioners Convention
January 2007

Evidence submitted by the NHS Alliance (PPI 81)

1. What is the purpose of patient and public involvement?

1.1 If harnessed correctly, properly resourced and implemented effectively, PPI could change the face of the NHS. It has significant vote-winning potential. When local people are meaningfully involved in the running of their local health services with positive change as a consequence, a virtuous circle of development can follow. The purposes of PPI are:
— At a community level: to ensure that local people are involved in the planning, the monitoring of new services and the improvement of existing ones.
— At an organisational level (practice/hospital): to ensure accountability for practice development and practice services.
— At an individual level: to ensure shared decision-making to the extent that the patient wants it, offering the informational support that the patient needs.

1.2 In addition, if community development is used as a key approach to PPI, an additional important outcome is significant health gain through the fostering of social networks. And greater self-care.

2. *What form of patient and public involvement is desirable, practical and offers good value for money?*

2.1 LINKs could offer excellent PPI if given the correct support and organisational frameworks (see later). We know from MORI studies that people want services to be:
— Representative but also local.
— Independent.
— Accessible with a wider range of people to be involved.
— Accountable.
— Change needs to happen as a result of PPI.
— There needs to be a democratic process underpinning PPI.

2.2 We know, from the same source, that people want to influence:
— The development of new services.
— The improvement of existing services.
— The monitoring of quality.
— The minimising of waste.

2.3 The approach that will work best, in the view of the NHS Alliance, has to have the following characteristics:
— Creates engagement without exhaustion for clinicians, the patient and publics. Brief liaisons are OK.
— Is flexible, drawing in a range of people in different ways and in different places.
— Challenges but can also co-operate with the establishment.
— Obtains rich ideas and recommendations.
— Gets changes made.

2.4 We think that community development is the key. Community Development (CD) is a process that mobilises communities to become participants in both defining problems and developing solutions to health and health service issues, and that reaches out to those most likely to be excluded.
— CD works with individuals and communities.
— It promotes health by bringing people together in social networks.
— Outreach flexibility.
— Its *raison d’être* is to get local voices heard and to support change.
— Interdisciplinary because it listens to what local people say—links regeneration and health.
— Light on practices, patient and publics.

2.5 There are a number of examples of good practice, where CD is linked to the workings of the PCT and the local authority. I can offer more details on these.

2.6 We also think that PPI needs to be promoted in practice-based commissioning (PBC). At the moment, despite exhortation, PPI is poorly represented in PBC. Local people should be involved in defining PBC cluster priorities, improving pathways, spending savings, monitoring quality. I can offer more details on this.

2.7 The NHS Alliance recommends that LINKs should bring existing groups together, should harness the CD activity that is already happening in their area and should be represented on all key groups in the PCT and in PBC clusters.

2.8 Patient access to the full GP record is essential to ensure PPI at the individual level of shared decision-making. Tailored information provision is the key, so long as the data is linked to good accredited health information that makes sense of what the patient is seeing. This is available now and promises to revolutionize care. Full record access has been shown to:
— Increase trust in clinicians.
— Improve relationships with their practice.
— Improve compliance in medicine-taking.
— Encourage preventative health behaviour.
— Enable patients to obtain their own health information without needing to contact the practice (allergies, immunisations).
— Empower patients to care for themselves more effectively.
— Use consultations with their clinicians more effectively.
— Save time for themselves and the practice.
— Correct errors in the record.

2.9 These are significant benefits and are summarised on the ICMCC website http://recordaccess.icmcc.org By designing appropriate and additional functionality, benefits can be enhanced further.

2.10 There are real advantages to the patient (quite apart from ethical considerations) in enabling access to the full record. This goes beyond current plans for HealthSpace and the Committee should support this development. I can offer more details on this.

3. Why are existing systems for patient and public involvement being reformed after only three years?

3.1 Although the NHS has got much better in the last 10 years at listening to what local people recommend, there is little evidence that the recommendations have led to much change.

3.2 The key limiting factor is that NHS organisations are not flexible and they remain unaccountable. There is no overriding reason why they should listen to local people. This is why the system is felt to need changing.

3.3 A serious worry in the current incarnation is that there still remains no guarantee that a PCT or a PBC cluster will HAVE to listen and HAVE to respond to its population. The Committee should insist on process that goes beyond Section 11: this demands that NHS organisations listen, but does not actually insist that they respond to local recommendations. The original suggestion was that new legislation would be developed that insisted that NHS organisations responded to local recommendations. This has got stuck, as I understand it, and is in danger of disappearing—the Committee needs to pursue it.

3.4 In addition, in order to keep PPI high on the agenda for NHS organisations, the HealthCare Commission needs to ensure that its developmental standards are rigorous and stretching for Trusts and that the PPI elements from a significant part of the scrutiny.

3.5 In our view, tipping the scales with petitions is not the way to go. They do not allow for planning and they can be hijacked by special interests.

3.6 Another reason that reform has been called for is that CPPIH’s recruitment process was complex and excluded many people—as a result PPI Forums were less inclusive and effective than they could have been.

4. How should LINks be designed, including

4.1 Remit and level of independence: they should be as independent as possible, both from the NHS and from the LA. The LA’s supervisory role may cause problems here.

The remit needs to be as broad as the three points at the beginning of this submission. LINKs should see themselves as umbrella organisations that harness the energy and experience of grass-roots organisations in the area. They should see themselves as focusing that heat and light on getting patient-centred change.

4.2 Membership and appointments: for maximum efficiency, LINKs should draw on as many local voluntary agencies as possible, all of whom should have a stake in the LINK. Any individual who wants to be part of the process should be able to join. The prime approach should be to have as open an organisation and process as possible.

4.3 Funding is essential for:
— Staff training.
— Admin.
— Contributors’ time—there are now many effective schemes for paying local people for this kind of work.

4.4 Support will be needed for:
— Training.
— Ensuring the right approach is taken—non-deferential and intent on securing the best arrangements for patients.
— Maximising the use of community development.
— Understanding how patient record access can make a real difference to care.
— Understanding aspects of the new NHS, including practice-based commissioning.
— Understanding how to use the powers LINKS will have.

The Centre for Public Involvement at Warwick University will be an excellent institution to support LINKs.

4.5 Areas of focus: the agenda should be set by local people. However, linking with PCT and Trust priorities will need to part of the mix. Again, LINKs should be seeing themselves as umbrella groups coordinating grass-roots work. They need to be on all key Trust committees which means they will need a lot of people.

It will also be helpful if they encourage/cajole/insist on good PPI practices in their Trust(s). PPI process should be embedded in all aspects of the organisation(s). This is currently rarely the case.

4.6 Statutory powers: LINKs need to be able to inspect wherever and whenever they want. If they are backed up by Section 11 and any new legislation, they will have a solid basis for intervening when needed. Training will be needed to emphasise this.

4.7 Relations with local health Trusts: if relations are poor, little will be achieved. An aggressive approach will not work. PPI services should support clinicians. They should be, if possible, not confrontational, facilitating patient panels and PPGs, helping practices respond to the wider determinants of health. They should foster an approach that says: “we are in this together, trying to improve care for patients.” If all that fails, they will invoke the law.

4.8 Relations with OSCs: I add this item. I am concerned that OSCs will not have the capacity to deal with the volume of activity that is likely to be generated by an efficiently working LINK organisation. Short of increasing their workforce, I cannot see a way round this.

5. How should LINKs relate to and avoid overlap with

5.1 Local Authority structures including Overview and Scrutiny Committees: I understand that the LA will usually host the LINKs and will offer support and research/audit. Funds will also flow through the LA. The LA will not have any regulatory function with regard to LINKs.

As suggested above, LINKs need to be as independent of the LA as possible. This may need emphasising given the closeness of working. If LINKs see themselves as umbrella agencies, they are less likely to duplicate work with the LA. Close working will make the use of community development more likely, as the LA will be the most ready source of CD expertise and activity.

5.1.1 A good relationship with the OSCs is essential. OSCs will be able to more in depth work on specific issues than LINKs. So long as coordination is maintained, overlap should not be a problem.

5.2 Foundation Trust boards and Members Councils:

5.3 Inspectorates including the Healthcare Commission (HCC): as mentioned above, the HCC needs to develop a robust PPI agenda and developmental standards. The LINKs can harness the findings of the HCC, for instance to bolster its own work. It may be able to call on the HCC to investigate specific issues. The HCC should be able to use the LINKs’ investigations and conclusions for its own reports. In summary, there are mutual interests, on the whole.

5.4 Formal and informal complaints procedures: LINKs should be in touch with PALS which accumulate data on complaints. The LINKs should not transgress on PALS's territory and should not receive complaints directly. LINKs should be working with PALS to remedy the causes of the complaints.

6. In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

6.1 It depends what you mean. The job of the LINKs is to develop processes that seamlessly and painlessly enable informal public consultation all the time under Section 11. If the system is working well, it would be easy for a PCT to find out what local people feel about their cardiac services and what recommendations for change they may have. It should also be easy for local people to generate an agenda for change in, say, sexual health services if that is seen by them as a priority.

6.2 Formal consultation needs to be instituted when:

— A significant change is being proposed.
— A petition with enough names on it is submitted (if this approach is continued).

7. In summary

7.1

— PPI can be seen as occurring at three levels.
— LINKs should be umbrella organisations which flexibly “harvest” local views. They will enable local people to dip in and out of engagement when they want. They will also enable clinicians to dip in and out, so that no-one gets exhausted.
— Community development is a vital approach to ensure good engagement of local people, effective outcomes and health gain.
— PPI must get changes made.
— Patient access to their full electronic GP record is essential for effective shared decision-making at the consultation.
— The NHS must ensure that organisations have to be made and/or incentivised to respond to local recommendations.
— LINKs should be as independent as possible, setting the agenda from local people’s views.
— LINKs need to work cooperatively with local health organisations so far as possible.
— Petitions are not recommended as a viable way forward.

Brian Fisher, GP
PPI Lead for the NHS Alliance

Evidence submitted by the NHS Confederation (PPI 142)

The NHS Confederation is a membership body that represents over 90% of all statutory NHS organisations across the UK. Our role is to provide a voice for the management and leadership of the NHS and represent the interests of NHS organisations. We are an independent organisation.

The NHS Confederation welcomes the opportunity to give evidence to the Health Select Committee on patient and public involvement. This evidence sets out our views, based on feedback from a cross section of our member forums.

Key Points

In today’s climate of patient choice and system reform, patients can vote with their feet. But this is not enough. Patients and the public must be allowed to have a say about changes in services at the outset, not at a point when decisions have already been made.

The way we involve patients and the public at the local level must be robust but flexible, enabling a variety of mechanisms to be used depending on the needs and circumstances of communities and their populations.

Patient and public involvement should empower patients and the public and make the NHS work differently. If individual citizens are to feel they are in the driving seat of the public services they use, then there must be opportunities for them to express opinions and have them heard, and to select outcomes which are particularly appropriate to them.

The NHS Confederation welcomes the expansion of LINks and the abolition of Patients’ Forums, as they should provide a more effective platform to involve patients and the public in health and social care. However, these networks need to be sufficiently independent and strongly embedded in the local NHS to work effectively.

We consider the valuable skills and competencies of those people already involved in Patients’ Forums to be vital and ones which should not be lost. These people should be actively encouraged to participate in the new networks.

We see the duty on each local authority to create and develop LINks as an opportunity to develop NHS organisations’ ability to reach the most deprived communities, which local government has traditionally been better at achieving through more developed consultation mechanisms.

1. What is the purpose of patient and public involvement (PPI)?

1.1 The purpose of involving patients and the public is to ensure that local populations get services that match their needs and requirements and that they have a say in how those services are planned, structured, implemented and delivered.

1.2 There is an important difference between involving people and consulting people. Involvement should be part of everyday practice for both commissioners and providers. All NHS providers of services should have a duty to engage and involve patients and the public but, particularly where service review or change is considered, only commissioners, with their accountability to the local community and links to Local Authority Overview and Scrutiny processes, should be duty bound to formally consult. Commissioners and providers should ensure that the need for, the design and the quality of local health and social care services are regularly market tested, including surveys to measure patient and public satisfaction.
1.3 In addition, it is important to note that involving patients and involving the general public are not identical processes but require quite different approaches. What matters to the patient usually focuses around their care and treatment whereas the public tends to look at issues from a position of value for taxpayers' money.

2. *What form of PPI is desirable, practical and offers good value for money?*

2.1 Involving patients and the public is by no means a new concept, but one that has undergone a number of changes in recent years to ensure that it adds value to the planning and delivery of healthcare. In the past, involving patients and the public has been seen as a good thing, but it has not been firmly embedded within everyday business practices and processes in the NHS.

2.2 Learning from past experience and the Patient Forum model tells us that we should be developing a model that allows patients and the public real opportunities to influence their local services in innovative and flexible ways that suits them. This must be underpinned by greater accountability and independence for those involved in this work. This means allowing LINks to be more flexible than the Patient Forums in terms of how they organise themselves and their membership and what work they undertake as the priorities and levels of enthusiasm will vary between local communities.

2.3 Involvement and engagement on an on-going basis means ensuring that patient and public satisfaction and experience is regularly surveyed and measured to ensure innovative ways of involving members of the community in issues that matter to them.

2.4 Processes that are well thought through, coordinated and add value to the way services are planned and delivered will provide good value for money.

3. *Why are existing systems for PPI being reformed after only three years?*

3.1 PPI Forums and the Commission for PPI in Health achieved a great deal, but the successes were not consistent across the country nor did they allow for sufficiently flexible arrangements to enable a more representative part of community to take part. The remit of the Patient Forums was not clear and there were conflicts between delivery and the public's expectations of what they could realistically achieve.

3.2 Involving patients and the public require quite different engagement methods and without recognising this any measure would inevitably be met with severe challenges. The NHS Confederation therefore wants to see a more coherent vision for involving patients and the public, underpinned by defined roles, remit, and accountability. But we want the functions and areas of focus to be determined locally. There is no one prescriptive model that could satisfy the needs of all communities. It is therefore vital that LINks are set up with sufficiently flexible arrangements and independence so that they can undertake their role effectively.

4. *How should LINks be designed, including*

   — Remit and level of independence

   As mentioned above, it is essential that the remit of the new LINks is clear and defined to avoid confusion that will not only lead to disappointments in terms of delivery but will also prevent meaningful recruitment and appointment to posts. It is vital that the LINks are and are seen to be independent as they will need to provide a balanced approach and use their influence in ways that does not place them too close to the issues affecting individual NHS organisations. This means being objective and not positioned too closely with any particular NHS organisation within the area. Placing the LINks within Local Authorities is a way of insuring this independence, as long as the role of the OSC is also clear and not extended to scrutinising strategic NHS decisions or outcomes. The role of the OSC must be concerned with processes and the role of the LINk independent in so far as it is there to facilitate better involvement and engagement and ensure any issues linked to local politics are resolved.
— Membership and appointments
The NHS Confederation believes that membership of LINks should be inclusive and reflect the diversity of the community it serves. It must reach out to minority and deprived communities through sophisticated involvement mechanisms and support. The case examples attached highlight some of the ways in which trusts are already using innovative methods to reach out to minority groups. In order to avoid conflicts of interest, membership should not be extended to include NHS or Local Authority staff.

— Funding and support
Funding is clearly a fundamental part of the success of the LINks. The funding given to Local Authorities should be ring-fenced to ensure that it cannot be absorbed into other initiatives. Dedicated support and expertise is required to make them a success and there should be clear connections with Patient Forum members etc to ensure continued learning and development so that all experience gained in the last few years is not lost.

— Areas of focus
To avoid being overly prescriptive, something which the Patient Forum model has been accused of, the focus of the LINks must be determined locally according to local populations and requirements which will rely on robust and up to date information obtained from a wide range of sources. LINks will need to engage with as wide a stakeholder community as possible to ensure they act on the best available information. This could include engaging with PALS, relevant community groups, support groups, local transport and anyone else who may have an interest in the planning and delivery of services. The LINks should be seen as both the seeker of information as well as a source of information to be utilised by others such as commissioners.

— Statutory powers
It is essential that the powers of LINks are defined in law, for example the relationship with the Overview and Scrutiny Committees, in order to clearly set out their consultation powers ie the right to be consulted. They should not have powers of inspection as the Forums did, as this appears to be an unnecessary duplication of the right of the OSC to scrutinise and challenge.

— Relations with local health Trusts
LINks should make every effort to inspire cooperation, collaboration and participation from local stakeholders as mentioned above. It is essential LINks form close relationships with all local health bodies and act as the “mechanism” through which good engagement, involvement and consultation takes place.

— National co-ordination
The NHS Confederation would support the proposal for national coordination and oversight of the work of the LINks but not the creation of a separate body to undertake this function.

5. How should LINks relate to and avoid overlap with

— Local Authority structures including Overview and Scrutiny Committees
LINks should have a close relationship with OSCs to ensure that the two cooperate. LINks should be able to participate in OSC activities such as reviews and OSC should likewise be able to feed their experiences and lessons learnt into LINks. Where matters are referred by the OSC to the Secretary of State for Health, there ought to be a limit on the time the Department of Health can take in responding to ensure that no unnecessary delays are experienced.

— Foundation Trust boards and Members Councils
When there is a critical mass of foundation trusts there will be well over a million members and thousands of governors. As well as being committed to the development of their own foundation trust, members and governors are also interested in far wider issues of health and care than simply those issues covered by their membership organisation. As such, they represent a dynamic force in communities and offer a good opportunity to make a strategic input in health. LINks should build on this resource and develop strong relationships with foundation trust wider governance structures. The way this is done should be determined locally rather than through nationally prescriptive guidance.

— Inspectorates including the Healthcare Commission
LINks should provide information on engagement and involvement to the Healthcare Commission as part of the Annual Health Check. However, this arrangement must ensure that there are no duplications for information requests placed on health bodies.

— Formal and informal complaints procedures
The NHS Confederation thinks that the LINks should oversee complaints made to NHS organisations but not necessarily be the receiver of such complaints.
6. In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

6.1 The NHS Confederation believes that involvement and engagement with the local population and service users should form part of the everyday working practices of both providers and commissioners. This is vital not only to ensure that patients and the public have a real say in services that matter to them, but also to ensure that services provided match the needs of the population. This should be done through testing patient experiences and satisfaction regularly, using surveys, conducting research etc. This requirement could be included in the contracts that commissioners have with providers for example.

6.2 The duty to conduct public consultation on substantive changes and reconfiguration of services should, however, fall on commissioners, not on providers. The reason for this is that it is the commissioner who is responsible for the services provided and accountable to the local community. It is vital to note the distinction between on-going involvement and market testing to ensure services are fit for purpose and the need for public consultation on reconfiguring services. To require providers to undertake public consultations on changes to services would add considerably to the bureaucratic burdens and would not necessarily add value to the concept of patient and public involvement.

6.3 Where public consultations are necessary, i.e. where there are significant changes to the provision of services, they should be conducted with the full involvement of both LINks and OSCs and planned in a way that allows the local population to have an input in decisions made, and not merely as a tick-box exercise.

**Additional Comments**

In addition to the above points, the NHS Confederation would like to stress the importance of robust governance arrangements for LINks. It is essential that the lines of accountability are clear and that there is some form of performance assessment of the LINks that will ensure they are meeting their obligations. Although we understand that non-prescriptive arrangements for LINks and their roles may be favourable to ensure they have the flexibility to be creative and effective, there need to be robust ways of holding them to account and how poorly managed LINks will be dealt with.

Attached at Annex A are two PCT case studies which have been particularly innovative in involving young people and carers, something which has traditionally been difficult to do and examples from a number of Foundation Trusts about how they have engaged patients and the public through their new governance structures.

NHS Confederation

January 2007

**Annex A**

**Richmond and Twickenham PCT**

*Mystery shopping project on sexual health services information used by young people*

This project demonstrates a supportive way in which young people can be involved in actively evaluating services using a “Mystery Shopping Project” approach. This method involves turning up at services presenting as an ordinary service user, and then completing a survey. The aim of this piece of work was to listen to, take seriously and act upon the recommendations offered by young people. The project involves both consultation work and participation of young people.

This project was done in partnership with the RT PCT Young People’s Sexual Health Worker, Education and Children’s Youth Participation Worker, Voluntary Services, Family planning services and Young People’s Walk In Services in Richmond, GUM Clinics from the Hounslow, Kingston and Wandsworth PCT’s and young people. 22 service evaluations were completed, and tangible recommendations were made for the future delivery of services. A full report and video of the exercise are nearing completion.

**Ealing PCT**

*Patients and carers choose a home tube feeding service*

Ealing PCT has used a tender process for home tube feeding services that involved patients and carers. Home tube feeding is successfully used for a large number of people who are unable to meet their nutritional requirements orally for a prolonged period of time. Ealing PCT and Ealing Hospital worked together with service users in the tender process for an enteral feeding contract. Companies set up a market place with stalls in Ealing town hall and gave presentations to patients and carers.
The majority of participants were carers rather than patients as patients needing the feeds tend to be either very young or very old and it is usually the carers who use tube feeding products. In the tender process carers were encouraged to challenge the companies’ claims about service quality—something they are not generally used to doing.

The patients/carers’ responses were weighted over those of staff and this helped influence the final decision which identified savings in the region of £220,000.

FRIMLEY PARK HOSPITAL NHS FOUNDATION TRUST

Foundation Trust Governor/Member Constituency Meetings

Frimley Park Hospital is involving local patients and the public—their members—in constituency meetings which have now been running for over a year. These are led by their governors, elected by the members themselves. Six constituency-based meetings were held in the autumn of 2006 spread geographically across the local area. Nearly 400 foundation trust members, patients and members of the public attended these events. Each meeting had a clinical focus and also incorporated a strategic planning update followed by the governors conducting an Open Forum session. A board member attended to hear the public’s comments and take questions.

Following the success of the meetings, governors have agreed that they should be held two to three times a year. Frimley Park is one of the first foundation trusts to hold members’ meetings. These are now seen nationally as an example of good practice and others are developing similar ways of meeting, and listening to, their local populations.

LANCASHIRE TEACHING HOSPITAL NHS FOUNDATION TRUST

Oversubscribed for “Focus on”

Lancashire Teaching Hospitals NHS Foundation Trust has held a number of successful members’ events based on clinical subjects, which have proved so popular that each has been oversubscribed. They have followed a “Focus on” theme, so far covering diabetes, bowel cancer and the work of its cancer centre. A networking session between members and governors is included within the programmes and feedback forms are made available.

STOCKPORT NHS FOUNDATION TRUST

Championing youth governors

The constitution at Stockport NHS Foundation Trust allows membership from the age of 16 onwards. However the trust is keen to ensure that the views of children and young people are actively heard. They have a dedicated appointed Youth Governor on their Board of Governors, recruited from, and supported by, the local Corporate Youth Service. They have also established a Young People’s Engagement (YPE) Committee—with membership from governors and representatives from internal and external agencies, chaired by the youth governor.

BROMLEY HOSPITALS NHS TRUST

Preparing local people to become foundation trust governors

Bromley Hospitals NHS Trust is in the preparation stage of applying for foundation trust status. It currently has a public, patient, carer and staff membership of 8,700. Its membership is strong and the trust continues to recruit members and is actively preparing local people to become foundation trust governors. Those expressing an interest in becoming governors are invited to attend potential governor workshops to introduce them to the trust. The high level of interest has resulted in two evening workshops in the last six months and a further one planned for January 2007.

SOUTH STAFFORDSHIRE HEALTHCARE NHS FOUNDATION TRUST

Governors’ and Members’ Involvement in Service Development

Carers, as well as staff, at a mental health in-patient facility for older adults at South Staffordshire Healthcare NHS Foundation Trust are helping to improve facilities for patients. They have recently been central to discussions and decisions on such projects as creating a garden and a Reminisce and Relaxation room for the use of service users. Members agreed that these would be of great therapeutic value and would enable a calm and harmonious environment to be created on the Unit.
Evidence submitted by the NHS Centre for Involvement (PPI 129)

1. BACKGROUND

1.1 The NHS National Centre for Involvement is a consortium of The University of Warwick, The Centre for Public Scrutiny (CfPS) and LMCA—an alliance of patient organisations. The Centre is hosted by The University of Warwick. The Centre aims to support the NHS as a whole, at local provider, regional and national levels to lead and sustain patient and public involvement in delivering NHS services to improve the quality of care and the efficiency and responsiveness of healthcare organisations.

1.2 The Centre was awarded to the consortium based on an EU-wide competitive tender with the results announced by Rosie Winterton on 23 May 2006. The set-up phase of the Centre started 1 June 2006 and the formal launch took place in London in November 2006.

1.3 The NHS Centre for Involvement welcomes the invitation from the Health Select Committee to submit evidence to its inquiry into patient and public involvement (PPI).

1.4 We recognise the circumstances in which the Health Select Committee is carrying out its inquiry. The committee called for evidence at the end of November 2006. Since then, the Government has published its response to “A stronger local voice” as well as the Local Government and Public Involvement in Health Bill.

2. What is the purpose of patient and public involvement?

2.1 The NHS Centre for Involvement believes that there are different categories of Patient and Public involvement (PPI). These range from working on an individual basis around treatment decision making, involvement in teaching and learning for health and social care professionals, setting research agendas and participating in the process, quality assuring healthcare education and training and evaluating service provision and developing services (including commissioning). All of these different categories are dependent on developing relationships across communities but with a change in emphasis from just providing feedback to being able to be involved and influence practice, process and strategic decision making. The Centre recognises the primary purpose of involving patients and the public at an early stage is to ensure that all those who manage and deliver healthcare services—as commissioners, providers or the Third Sector—take into account their needs and concerns in carrying out their role.

This must include PPI work at “service improvement” level (in directorates, teams, areas, etc) and at a corporate/strategic level. It is essential that this approach is based on an understanding that health and social care should meet the needs of patients and the public.

Those organisations commissioning and providing services should be flexible and responsive to the needs of patient and the public within the parameters of organisational capacity and budgetary constraints.

2.2 The Centre also believes that effective PPI should enable a publicly accountable model facilitated through an ongoing “accountability relationship” whereby patients and the public and healthcare managers, professionals, staff and organisations have opportunities to “give and receive accounts” of the service. This should include formal and informal opportunities for patients and public, whether as individuals or groups, to voice their needs and concerns directly and indirectly to managers and clinicians at all levels of healthcare provision including professional training.

3. What form of patient and public involvement is desirable, practical and offers good value for money?

3.1 Effective PPI should be nurtured so that it grows organically within and around healthcare organisations as part of a “public facing” culture. Opportunities need to be provided for patients, carers and the wider public to have clear and flexible opportunities to be involved (directly or indirectly), share experiences and influence the future services and learning in a range of ways:

- As individuals—through relationships with clinicians as “expert” patients—and through more formal complaints procedures/advocacy arrangements
- As groups or communities of interest (based on geography or medical condition)—through opportunities to advance particular causes or concerns in relation to available services and treatments
- As representatives of local communities and the public—as non-executive directors/governors and elected representatives on Trust boards or Health Overview & Scrutiny committees or in other relevant bodies

3.2 An appropriate relationship between individuals and groups with and through elected or appointed representatives is one mechanism for ensuring the practical approach and best value for money. Other forms of accountability, however, are also essential.

3.3 It should be recognised that practical patient and public involvement is not just about techniques, nor is it about structures. The Centre suggests that it is dependent on clarity of aims and objectives and making sure that changes result on the basis of the involvement. Patient and public involvement activities and the impact they have on service provision must be understood in the context of high quality evidence.
3.4 All staff whether providing or commissioning services, or supporting health and social care services must be trained and supported to do high quality PPI. This will ensure that their work is shaped by the views, experiences and priorities of patients and the public.

4. Why are existing systems for patient and public involvement being reformed after only 3 years?

4.1 The NHS Centre for Involvement believes that the implementation of the Health and Social Care Act 2001 has resulted in more effective local authority health overview & scrutiny committees. The proposed system reform is an opportunity to rebuild in the light of experience and ensure greater clarity of complementary roles and responsibilities across the health and social care spectrum.

4.2 The Centre believes that once the reform of the system takes place it will require a period of stability in order to be integrated into everyday practice in the NHS and Social Care, generate trust from local people and health and social care professionals and attain its full potential for driving locally responsive high quality service provision.

5. How should LINks be designed?

5.1 The Local Involvement Networks (LINks) should be designed within a framework which allows for as much local discretion as possible for LINks to operate effectively.

5.2 The purpose of LINks is to ensure that in each locality there is a network which patients and the public can join, and which healthcare organisations can consult with to make sure that local needs and concerns are communicated as and when appropriate eg in relation to commissioning, new service provision, service reconfiguration, service evaluation, addressing local health inequalities.

5.3 Each LINk should have as a minimum a local co-ordinator with an appropriate level of administrative support and a permanent and visible base. Each LINK should then agree what formal arrangements are needed to operate effectively. If needed a number of options for good governance of LINks could be made available, eg organising committee/board/local chair. LINKs should provide regular formal opportunities for local discussion and debate about local health issues. LINks should also be required to generate annual priorities, in conjunction with relevant NHS/Social Care organisations and in partnership with their community. This would offer a balance of being able to meet national health and social care priorities together with satisfying perceived local needs.

5.4 LINks should not be formally connected to any one health or social care organisation but should be independent of all. Their remit should be to advance the voice and concerns of patients and the public in response to local need and experience. Local health and social care organisations should approach LINks as part of their duty and responsibility to consult patients and the public.

5.5 As a network organisation, each LINk through its co-ordinator, will connect with existing local and regional voluntary and community groups involved in health and social services as well as local authority community development organisations. It is likely that these groups will be in a position to generate support and practical advice which LINks can tap into to become a robust local voice for patients and the public. These organisations should have a range of forms from charitable trusts through to user-led groups.

5.6 LINks should be a key source of information about local services, from public, private or voluntary sector organisations, to the regulatory authorities (the Healthcare Commission and the Commission for Social Care Inspection).

6. How should LINks relate to and avoid overlap with other organisations?

6.1 LINks should be regarded as a body that strengthens local public accountability for local health and social services. The LINK should develop constructive working relationships with all NHS social care bodies including Foundation Trusts and the Health Overview & Scrutiny Committee.

6.2 LINks must also build on and use existing information available in their locality. For example, large amounts of information is already gathered through PCT and Trust patient surveys, the Annual Healthcheck conducted by the Healthcare Commission, public health data and health plans from NHS organisations.

6.3 LINKs need to be well positioned to strengthen the interface between service and workforce development by ensuring that the views and experiences of patients and the public inform and influence education commissioners.
7. In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

7.1 The NHS Centre for Involvement believes that key to commissioning high quality health and social care services is the involvement and understanding of the needs of local communities. We believe that every opportunity should be made available for patients, the public, carers and users of health and social care services to be involved at the start of any changes to services and to help shape those changes.

Ian Brittain
NHS Centre for Involvement
January 2007

Evidence submitted by the National Consumer Council (PPI 114)

Further to your correspondence of 18 December regarding the Committee’s inquiry into Public and Patient Involvement in the NHS, I am pleased to respond with further information.

I am attaching two reports which detail key recommendations further:

— Final Report from Having My Say Taskforce, which met in October/November 2005 to find ways to promote people’s ‘say’ in health and social care so that services develop in ways that are genuinely responsive to their needs and choices. I chaired the Taskforce in my capacity of Chief Executive of the National Consumer Council (NCC).

— Department of Health Concluding the review of patient and public involvement: Recommendations to ministers from Expert Panel, which reported in May 2006. I co-chaired this panel.47

For ease of reference I am detailing the main recommendations from each report.

A. KEY RECOMMENDATIONS FROM HAVING MY SAY TASKFORCE

1. The ability of people to have a say is essential to ensure that high quality health and social care services are available to meet their future needs.

— People, as active or potential service users and as members of the public, want to be able to have a better say in relation to health and social care services. Those services are better all round when the views and experiences of people using them are systematically taken into account. Without such a say, they are significantly less effective.

— Service users should have a say through the individual choices they make and encounters they have with professionals. But they also need a say in shared ways, to shape what choices are on offer and to ensure that more vulnerable users do not lose out.

2. The right kind of involvement is needed at every stage of the design, delivery and evaluation of services.

— There should be an involvement with service users and the public at every level at which decisions are taken in health and social care.

— The responsibility for giving service users a say should rest with the decision makers responsible for commissioning and providing services.

3. The quality of involvement matters but can achieved in different ways.

— Arrangements to engage people need to be simple, visible and consistent across local services. And they need to include the voices of more vulnerable service users, who may not always be heard.

— An effective way to promote a culture of involvement is to build more inclusive governance into programmes of health and care.

4. There needs to be a systematic way of encouraging decision-makers to listen and to respond to what they hear.

— There should be a less prescription on the structures decision-makers use to engage, to allow for more creative approaches, but an increased focus on their accountability, through scrutiny, inspection and regulation, for the quality of engagement and their responsiveness to it.

— There is a need to recognise and support the independent voice of voluntary organisations in shaping services for users.

47 Not printed here.
B. KEY RECOMMENDATIONS FROM DEPARTMENT OF HEALTH CONCLUDING THE REVIEW OF PATIENT AND PUBLIC INVOLVEMENT RECOMMENDATIONS TO MINISTERS FROM EXPERT PANEL

1. We recommend a more flexible framework for supporting public and service user voices in health and social care at the local level. This should draw on the strengths of voluntary and community organisations and on interested individuals, build wherever possible on existing or developing involvement structures and be more closely connected with the scrutiny function in local government.

2. We recommend the removal of the legislative requirements for Patient Forums. We recommend that a Local Involvement Fund is established to support a stronger public and user voice, with a clear mandate, adaptable to local circumstances. The mandate will be for the creation of what we call Local Involvement Networks (LINks) for health & social care.

3. Our preference is for non-statutory bodies, but we understand that it is not possible to achieve the formal relationship we want the LINks to have with statutory bodies such as OSCs and PCTs unless the LINks are defined in law. We recognise that the LINks will need to have some statutory basis for them to have rights of involvement and consultation drawn from the duties placed on PCTs and Local Authorities. If new statutory bodies are set up we strongly recommend that statute defines function rather than form.

4. We also recommend that a specific relationship is established between the LINk and the OSC—the LINk should have a formal right to refer matters to the OSC.

5. We recommend that OSCs should focus their reviews on the decision-making activities of PCTs and local authorities, in particular scrutinising how well they have met the requirements of the revised duties to involve, consult and respond.

6. We recommend the creation of capacity for a stronger voice for patients, service users and members of the public at the national level.

7. We recommend that commissioning organisations across health and social care should have a duty to involve and consult their communities at all levels.

8. We recommend that these duties to involve and consult should be clearly set out in the forthcoming commissioning guidance.

9. We recommend commissioners should be required, as part of their existing planning arrangements, to develop a forward plan for engaging service users and the public.

10. We recommend the commissioner should have a duty to respond to the community, as well involve and consult them.

11. We recommend that S11 is strengthened and its scope extended. The new section should require every body which is responsible for delivering health and social care services (commissioners and providers) to involve, consult and respond to users and the public.

12. We endorse the White Paper recommendation that duties to involve patients and service users should be extended to cover independent sector providers.

13. We recommend the simplification and rationalisation of the legislation around health service consultation.

14. We recommend that the legislation merging the regulators should set out how the single organisation will both regulate stronger voice and how it will involve users of services and the public and to put their interests at the heart of its regulatory activities.

15. We recommend that explicit assessment criteria are established to enable regulators to assess the performance of commissioners.

I hope that you will find this information useful and please do not hesitate to contact me if you require clarification on any issue.

Dr Ed Mayo  
Chief Executive, National Consumer Council  
10 January 2007

Evidence submitted by the National Institute for Health and Clinical Excellence (PPI 61)

1. SUMMARY

1.1 The National Institute for Health and Clinical Excellence (NICE) involves a wide range of stakeholders in the development of its guidance including NHS staff, healthcare professionals, the academic world, the pharmaceutical and medical devices industries, patients and carers, and organisations representing the interests of patients, carers and the public.
1.2 We take a structured approach to our engagement with patients, carers and the public that enables them to contribute to the development of NICE guidance and encourages them to work transparently, alongside other stakeholders.

1.3 NICE has a dedicated policy and a range of mechanisms for involving patients, carers and the public in the development, dissemination and implementation of NICE guidance. Opportunities for involvement are supported by a dedicated team (the NICE Patient and Public Involvement Programme, PPIP) which recruits, trains and supports lay contributors (both individuals and organisations) to NICE guidance.

1.4 The purpose of this memorandum is to consider how Local Involvement Networks LINks might develop, taking into account the resources that are potentially available to them from NICE. We have focussed on the potential for NICE activities and outputs to influence how LINks should be designed, in the following areas:

— National coordination.
— Remit and area of focus.
— Membership and appointments.

1.5 We recommend the following areas for action:

1.5.1 National co-ordination (1): We note from the Committee’s terms of reference for this inquiry that the focus seems to be primarily on local PPI structures. To ensure that different initiatives inform each other and to avoid unnecessary duplication of effort, we suggest that local PPI initiatives should not be considered in isolation, but in relation to national PPI activity, including NICE PPI activities.

1.5.2 National co-ordination (2): NICE has already started to develop relationships with PPI forums. Some forums have used NICE guidance to inform their local quality assurance work. Some have been proactive in ensuring that the patient versions of NICE guidance are better disseminated locally to end users of services. We suggest that the developing relationships between NICE and patient forums be extended and formalised with the new LINks.

1.5.3 Remit and area of focus: We take the view that those who receive services from the NHS should have access to the best evidence-based care available. We suggest that NICE guidance recommendations, based as they are on the best available evidence of both clinical and cost effectiveness, and incorporated into the Department of Health’s core and developmental standards, are important sources of information for LINks (as well as other structures such as Overview and Scrutiny Committees) to inform their activities. NICE guidance can be used by LINks and others to act as a lever for improving health and social care locally, and using NICE guidance means local LINks will all be working to help implement national standards of care, giving their work an emphasis on equal access to the highest standards of care for all. Specifically we suggest that LINks are supported to:

— understand the role of NICE guidance in promoting quality care;
— use the recommendations set out in NICE guidance to inform how LINks observe and assess the nature and quality of local services;
— encourage dissemination of patient versions of NICE guidance to patients at local levels so that individual patients can use this to inform decisions about their own care; and
— monitor uptake of NICE guidance and feedback to NICE and the Healthcare Commission so that this information can be used to identify both good practice and inconsistencies in uptake.

1.5.4 Membership and appointments: We understand that the membership criteria and recruitment processes for LINks members have not yet been finalised. NICE has developed open and transparent recruitment procedures for lay vacancies, supported by job descriptions and person specifications and clear selection criteria. NICE also offers training and support to patient groups and individual lay people involved in NICE activities. NICE would be happy to explore if its processes might be used by the new LINks initiative to recruit and support new members.

2. What is NICE?

The National Institute for Health and Clinical Excellence (NICE) is the independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health. Further information about the work of the Institute can be found at www.nice.org.uk.

3. Roles and Responsibilities of NICE

NICE produces guidance in three areas of health:

— public health—guidance on the promotion of good health and the prevention of ill health for those working in the NHS, local authorities and the wider public and voluntary sector;
— health technologies—guidance on the use of new and existing medicines, treatments and procedures within the NHS; and
— Clinical practice—guidance on the appropriate treatment and care of specific diseases and conditions within the NHS.

NICE has also set up a programme to help put NICE guidance into practice. Centrally located staff together with local implementation consultants:
— ensure intelligent dissemination to the appropriate target audiences.
— actively engage with the NHS, local government and the wider community to support implementation of NICE guidance and evaluate its uptake.

4. PATIENT, CARER AND PUBLIC INVOLVEMENT AT NICE

4.1 Since its inception, the Institute has taken the approach that those whom its decisions affect are entitled to express their views on how we go about our work and on the development of individual pieces of guidance. Groups affected by our decisions include patients, carers and the public, and those who speak for them.

4.2 NICE is committed to producing guidance that:
— meets the needs of patients, carers and the public; and
— involves patients, carers and the public in its development.

By working with patients, carers, patient organisations and the public, NICE aims to produce guidance that addresses patient/carer/public issues, reflects their views and meets their healthcare needs. In deciding which clinical treatments or public health strategies to recommend, a balance has to be drawn between the needs and wishes of individuals and the groups representing them, against those of the wider population. This sometimes means treatments are not recommended because the research evidence suggests they do not provide sufficient benefit to justify their cost.

4.3 The Institute actively involves patients, carers and members of the public in the development of all its guidance. This includes contributing to making the decisions (sometimes difficult ones) that have to be taken when recommending that the NHS should offer or refuse specific treatments. Opportunities for involvement include:
— Patients, carers and the public (both individuals and organisations) can suggest topics for future NICE guidance.
— National organisations representing patients, carer and the public are consulted on draft scopes (the documents that describe what a piece of guidance will and will not cover) and draft guidance recommendations.
— NICE advisory committees and working groups (including the groups that produce NICE clinical guidelines and public health programme guidance) include at least two, often more, patient/carer/public members.
— NICE works with patients, carers and the public to encourage dissemination and implementation of its guidance.

5. EXISTING COLLABORATION BETWEEN NICE AND PATIENT AND PUBLIC INVOLVEMENT FORUMS (PPIFs)

5.1 NICE has already developed relationships with PPI forums, exploring the potential for collaborative working and working with individual forums to identify ways in which they can contribute to the development of NICE guidance and encourage local dissemination and uptake of NICE guidance.

5.2 Patient forums have:
— Publicised vacancies for patient, care and public members of NICE committees, guideline development groups and public health programme development groups.
— Hosted events for local patient/public representatives to hear more from NICE and how it produces its guidance.
— Encouraged local dissemination of patient versions of NICE guidance to end users of NHS services.
— Used NICE guidance to monitor local services and promote uptake of NICE recommendations.

6. RECOMMENDATIONS FOR POTENTIAL COLLABORATION BETWEEN NICE AND LINks

6.1 We note from the Committee’s terms of reference for this inquiry that the focus seems to be primarily on local PPI structures. To ensure that different initiatives inform each other and to avoid unnecessary duplication of effort, we suggest that local PPI initiatives should not be considered in isolation, but in relation to national PPI activity, including NICE PPI activities.
6.2 We take the view that those who receive services from the NHS should have access to the best evidence-based care available. We suggest that NICE guidance recommendations, based as they are on the best available evidence of both clinical and cost effectiveness, and incorporated into the Department of Health’s core and developmental standards, are important sources of information for LINks (as well as other structures such as Overview and Scrutiny Committees) to inform their activities. NICE guidance can be used by LINks and others to act as a lever for improving health and social care locally, and using NICE guidance means local LINks will all be working to help implement national standards of care, giving their work an emphasis on equal access to the highest standards of care for all. We therefore suggest that the developing relationships between NICE and PPI forums be extended and formalised with the new LINks.

6.3 In determining the remit and area of focus for LINks, there is the potential for LINks to contribute to the production of NICE guidance, to use NICE guidance to inform their own activities and to encourage dissemination of patient versions of NICE guidance to publicise NICE recommendations to local patient populations. Specifically we suggest that LINks are supported to:

- understand the role of NICE guidance in promoting quality care;
- use the recommendations set out in NICE guidance to inform how LINks observe and assess the nature and quality of local services;
- encourage dissemination of patient versions of NICE guidance to patients at local levels so that individual patients can use this to inform decisions about their own care;
- engage with their local NICE implementation consultant; and
- monitor uptake of NICE guidance and feedback to NICE and the Healthcare Commission so that this information can be used to identify both good practice and inconsistencies in uptake.

6.4 We understand that the membership criteria and recruitment processes for Links members have not yet been finalised. NICE has developed open and transparent recruitment procedures for lay vacancies, supported by job descriptions and person specifications and clear selection criteria. NICE also offers training and support to patient groups and individual lay people involved in NICE activities. NICE would be happy to explore if its processes might be used by the new Links initiative to recruit and support new members.

7. Conclusion

LINks will operate as part of a wider context which aims to ensure that patients can access the best available care. To this end, there is potential for LINks to use NICE guidance to inform their own activities, to support the dissemination of patient versions of NICE guidance to local patient populations, and to monitor the implementation of NICE guidance as part of their quality assurance activities.

NICE submits this memorandum to raise this as a potential area of focus for LINks activity and to offer to work collaboratively with LINks to achieve this if it is incorporated into their remit.

Dr Maria Kelson
National Institute for Health and Clinical Excellence
January 2007

Evidence submitted by the National Association for Patient Participation (PPI 83)

1. The National Association for Patient Participation was formed in 1978 and is a registered charity. We are the umbrella organisation for Patient Participation Groups (PPGs) in primary care and currently have 280 affiliated groups (roughly 3% of English practices). Each of our members is unique with activities that respond to local need. Their functions include providing strategic advice to their practices, running health promotion events, providing advice and information, and delivering services such as volunteer transport, befriending, counselling and support to carers.

2. The National Association for Patient Participation welcomes the Health Committee’s Inquiry into Patient and Public Involvement in the NHS. The future design of the statutory structures is clearly important. We hope, however, that the Committee will also be able to take a wider view that embraces alternative models, including the work of patient participation groups within primary care.

3. There has been considerable progress in recent years in improving the patient experience and in developing approaches that see patients as one of the resources that will drive up quality and promote safety. But the development of the machinery of patient and public involvement has come at a considerable price.
4. We would urge the Committee to aggregate and evaluate the money currently spent in supporting CPPIH and the PPI Forums in England, on the patient experience component of the Quality Outcomes Framework, on the PALS and PPI officers in each Trust, and on the national patient surveys.

5. Our concern is that resources have been sucked into the “provider” side of patient and public involvement, rather than being shared more evenly with those organisations who wish to influence the NHS. The current approach is unlikely to lead to the desired outcome identified by the Wanless report whereby our society is fully engaged with its health which is worth, in his view, £30 billion annually by 2022.

6. In our view, there needs to be greater emphasis on continuing to change the relationship between patients and professionals so that a philosophy of partnership is created. This must not be overwhelmed by investing in monitoring, scrutiny and inspection (important though those functions are) which can reinforce divisions and set patients against the services. Instead, our structures of patient and public involvement should also encourage healthy relationships based on mutual respect, professionalism, openness and a joint commitment to improving the quality of care.

7. In short, patient and public involvement can be seen as a mechanism which protects patients against poor care and poor service. But we believe that it should also be seen as a method by which patients can become more engaged in their own health and by which professionals learn to recognise just how much patients have to offer.

Graham Box and Danny Daniels
Chief Executive and Chairman, National Association for Patient Participation
January 2007

Evidence submitted by Norfolk & Norwich University Hospital PPI Forum (PPI 27)

What is the purpose of PPI?

1. Just what it says—to involve the wider public in the decision making, provision and monitoring of everything involving health and social care. Also to obtain an outside view of the rather enclosed world of the NHS—we are told that this is very valuable.

What form of PPI is desirable etc?

2. At the very least, the form that the best PPI forums were able to build up during their short lifetimes. A “critical” friendship where the PPI viewpoint is sought, respected and valued. Also, the PPI Forum should be responsive to national and, more importantly, local needs and perspectives which may vary from one locality to another.

Why are the existing systems for PPI being reformed?

3. A very good question, because Forums, after a great deal of hard work, are already monitoring their areas and gathering public opinion; plus building relationships across the voluntary sector. But the extension to cover Social care is very welcome, although many Forums were already, quietly, doing just that. The emphasis away from organisations is damaging especially in the case of Acute Trusts, and more especially PFI Acute Trusts like ours. The new reforms should build on the best PPI experience by bringing the less efficient and effective Forums up to the same standard—in effect many Forums are already acting like LINks.

How should LINks be designed?

4. Firstly, with a great deal of care and thought—especially about what has been achieved and what were the mistakes of PPI Forums. Guarantee a long term with incremental improvements based on experience—not major change after three years as per change from Community Health Councils to PPI Forums.

Remit and level of independence

5. At least the same remit as PPI Forums to cover Social Care as well as Health. A critical friend plus statutory duties to monitor services and gather public opinion. With rights of inspection. Independence is vital especially from political pressures or the NHS itself.
Membership and appointments

6. Membership should be as open and inclusive as possible; but to involve younger working members, special arrangements must be made—perhaps giving consideration to companies to allow their employees to drop in and out of LINKS. There might need to be a two tier system of appointments for members who are able to carry out inspections with a fairly formal interviewing process. Consideration of paid appointees to guarantee that members who commit to longer than average hours get additional benefit (eg Chairs) and thus provide continuity.

Funding and support

7. This should be ring-fenced, robust (not able to be plundered by local government for other things in times of need) and upfront unlike that for PPI Forums; it should be adequate to allow for more publicity than PPI Forums had; and if working members are to contribute to allow for this. Also to allow for such things as meetings in public to be successful. Support is very important for arranging meetings, research and collating; and for general administration. But, more support is needed for marketing and publicity and perhaps less on the knowledge side.

Areas of focus

8. The whole patient pathway including social care provision. With special emphasis on under-represented and/or under-funded areas like mental health and care of the elderly. Also looking at commissioners and actual providers of care such as hospitals and homes, including the private sector (if things are not on the commissioning list they won’t get funded, so these people are key).

Statutory Powers

9. At least as strong as for Forums to include social care and the private sector; and to be well publicised. Government should undertake to act on clear recommendations made across the board, otherwise there will be little point in the whole exercise. It’s all very well to listen but that is not always enough, as has been proved often under the current regime. If volunteers can see that it is worth their while, they might be less reluctant to come forward. Lack of funds should not always be enough reason for Government to reject ideas/proposals.

Relations with local health trusts

10. The same as for Forums—to be included as equals in planning and decision-making (but Forums have learnt that trust and respect has to be earned).

National coordination

11. Vital for national campaigns like Foodwatch and for support, networking and training, but with more member input and fewer regulations. Again, results of such campaigns should carry more weight at Government level.

How should LINks relate to and avoid overlap with:

Local Authority structures including OSCs

12. Many OSCs are either unable or unwilling to cover health in breadth or depth and the LINks could play a major part in filling that gap; but workplans must be shared and where possible co-ordinated.

Foundation Trust Boards and Members Councils

13. There would seem to be more reasons for than against dual membership and sharing views etc.

Inspectorates

14. It is important that each knows what the other is doing and where possible that the two areas liaise/co-ordinate and do not overlap or clash. Make it a statutory obligation for Healthcare Commission (and others) to consult and/or liaise with LINks.
Formal and informal complaints procedures

15. It is important to be able to identify trends so it is beneficial if the Complaints departments give regular reports to the LINks/Forums and complaints have actually worked together to solve problems.

In what circumstances should wider public consultation be carried out?

16. When any change is proposed that will seriously affect the public—for example reconfiguration of services (e.g., bed closures, moving units, rebuilding) and any changes in PCT policy like patient records, rationing drug regimes and so on. It should not have to wait for the circumstances outlined in the white paper—such as, the unrealistic requirement for a high percentage of people to complain or show concern about a proposed change before that issue can be taken up.

Anthea Nicholson
Chair, Norfolk & Norwich University Hospital PPI Forum
5 January 2007

Evidence submitted by North East Ambulance Service PPI Forum (PPI 16)

The North East Ambulance Service Patient and Public Involvement (PPI) forum understands that your committee is gathering evidence before making recommendations to parliament regarding the future of PPI in Health.

As a Forum covering a specialist NHS trust we feel that combining us into a wider network will mean that issues relating to ambulance services will be subsumed into other larger issues. We feel that this will undo all of the good work that we have done over the last three years. Not only that but we will lose the excellent working relationship that has built up with our Trust.

We would like you to consider recommending that Forums based around such specialist services (i.e., ambulance, mental health, etc.) retain their individual identity allowing them to continue and build on previous work.

The evidence that we enclose is, we feel, strong enough to support our case for retention. As you will see we have carried out a number of projects, which we have presented to NEAS NHS Trust, who have then considered the reports we have presented, and they have always responded positively to them, and where necessary they have acted upon our recommendations contained within the reports. One prime example was of two surveys we carried out, one looking at patients’ experiences of Patient Transport Services (PTS), and the other, the efficiency and effectiveness of the PTS. These surveys were followed up by a report, which contained a number of recommendations, which the trust responded to and acted upon. We feel that this is obvious evidence that our current system is working and shouldn’t be tinkered with and incorporated into a wider network.

We have over the last three years built up a relationship with our Trust that is based on mutual understanding, trust and most importantly, respect, that we feel will be lost if we were to be merged within LINks.

In our particular case because we cover a huge geographical area (from Berwick in the north to the border between Cleveland and north Yorkshire in the south, and from the East coast to the border with Cumbria), it would so impractical to be forced to become part of a number of different LINks that cover that same geographical area.

We do hope that you will give serious consideration to our request and evidence, and we look forward to your recommendations to parliament, which hopefully will include one to retain the status quo with specialist forums. If you require any further information, please do not hesitate to contact me at the above address, and I will be delighted to assist you in any way I can.

Michael A Dalton
Chair, PPIF North East Ambulance Service PPI Forum
2 January 2007
Evidence submitted by North Tyneside Patient and Public Involvement Forum (PPI 51)

1. How should LINks be designed

1(a) Remit and level of independence

LINks should be clearly independent from both Local Authorities and the NHS. Their remit should be to monitor health and social services in a geographical area relating to local authority boundaries. They could be commissioned jointly by a consortium of Local Authorities to give a wider view and provide economies of scale. Where possible, the host organisation should have a proven track record, a clear understanding of Patient, Carer and Public Involvement and knowledge of the local health economy. To ensure impartiality, the selection of the successful host organisation should be decided by a group of people representing the Local Authority, the Community and Voluntary Sector, and possibly local PPI Forum members.

1(b) Membership and appointments

The host organisation (whatever its setup) will have guidelines in the form of their constitution, standing orders or Memorandum of Association. Membership should be by adherence to these guidelines. Therefore allowing for different levels of commitment and involvement by individuals and groups, This will enable LINks to further build on the experience gained by forums over the past three years and to recognise the contribution of those already involved. Ideally this will achieve true local engagement and independence but will require a process of evolution.

LINks must become the lead in the organisation, and have a central committee supported by the host organisation. This central committee democratically elected and unwavering in its duties would be responsible for guiding the whole range of activities agreed by LINks members.

1(c) Funding and support

Funding should come via the Local Authority/(ies) commissioning LINks. Additional funding could be applied for to carry out specific pieces of work within the area. To establish the independence of LINks, funding should not come from any part of the Local Authority that delivers Social Services.

Support should be from the host organisation commissioned to deliver the LINks by the Local Authority. When deciding on levels of funding, there needs to be an acknowledgement that if LINks are to be successful they must have appropriate funding. Reaching marginalised groups and individuals is expensive, and the funding must reflect this. Funding must allow for travel expenses, money to cover child care and carer expenses, and the cost of translators, interpreters and signers if these are needed. Such funding needs to be realistic and sustainable, recognising the importance of LINks.

It would be hoped that funds available be controlled and held accountable by the central committee locally and the host organisation, and not another national arms length body.

1(d) Areas of focus

The area of focus should be any area of service delivery provided by either the Local Authority, the NHS or commissioned private providers of services within the region.

1(e) Statutory powers

Although the local credibility of the LINks will be fundamental to how successful they are, it is important that some statutory powers are retained. This will ensure that Trusts, local authorities and commissioned private providers of services respond to LINks. Without the statutory powers, there is the possibility that some bodies will keep LINks at arms length and not treat their work with the importance and consideration it deserves. Retaining the statutory powers will enable access to all reasonable information and the expectation that service providers respond to formal reports when submitted.

The monitoring visits of the Forums have been one of the most successful aspects of the their work to improve conditions for patients and the public, eg monitoring of the local hospital wards staffing levels working jointly with the hospital forum looking at infection control rates in the local area.
1(f) Relations with local health Trusts

LINks should be a “critical friend” to the Trusts, Local Authorities and commissioned private providers of services they relate to. Service providers must have an obligation to respond to LINks at an agreed level in order for the LINks to be effective. LINks will be more productive where a positive relationship is developed between the LINk and the Trusts. This can be demonstrated over the past three years by the levels of trust and co-operation reached by many forums with their related NHS Trusts, this positive relationship has formed many partnerships and networks which must not be lost.

1(g) National coordination

A National overview for LINks at the very outset would be useful. One of the problems with the PPI Forums has been the difficulty in having a common voice on National issues. This organisation should not be an arms length body such as the CPPIH, but a “resource” with minimum staffing but having no powers over managerial or budgetary issues and exists to give support and guidance to both host organisations and LINks members. This organisation must work in partnership to give the best support to the LINks.

2. How should LINks relate to and avoid overlap

2(a) Local Authority structures including Overview and Scrutiny Committees

LINks and Overview and Scrutiny Committees should complement each other in the work that they do. There will be areas where they can work together, using their different statutory powers to undertake pieces of work that cannot be successfully done separately. Sharing work plans, experiences and skills will be essential. In this area ppifs have worked jointly with the OSC’s on issues such as changes to maternity services, dentistry and diabetic podiatry, using their powers of inspection and access to information unavailable to the OSC’s.

2(b) Foundation Trust boards and Members Councils

However effective members’ councils are, they are not independent, having a level of corporate responsibility to the Trust to which they belong. It is essential that LINks work with members’ councils in their areas, to give an independent view of issues within the Trust. For LINks to be really effective this is crucial, to enable the relationship with service providers to remain objective and as an independent critical friend.

Trust members may be able to contact LINks if they have particular areas of work they want to address. They can then use the statutory powers of the LINks to follow up on these issues or to carry out surveys or focus groups locally.

2(c) Inspectorates including the Healthcare Commission

The input of the LINks into the annual health checks for Trusts will continue to be important. The Healthcare Commission should not assume that the LINks are there to work on behalf of the Healthcare Commission, and the LINks must be free to decline to work for the Healthcare Commission if they feel it is inappropriate. LINks should be recognised by outside organisations as a place to be objective, to seek improvement in standards and to recognise and highlight improvements when achieved.

As an example of good practice, forum members held an informal visit to the regional Out of Hours service to find out if local negative press was true. The visit revealed this was not the case and a public meeting with the Chief Executive of Northern Doctors Urgent Care, who explained about this service dispelled many fears raised by the unfavourable press reports.

2(d) Formal and informal complaints procedures

When the various responsibilities of the Community Health Council (CHC) were split up, there was an understanding that they should link together to provide a co-ordinated Patients and Public Involvement structure. This has not happened with the Independent Complaints Advocacy Service (ICAS) which has been patchy to say the least.

In the shorter term, LINks will need to relate to PALS and ICAS, but in the longer term it would be good to see these two services transferred back to the host organisations that support the LINks.
3. **In what circumstances should wider public consultation (including under Section 11 of The Health and Social Care Act 2001) be carried out and what form should this take?**

   It is not so much the circumstances, but that consultations are “meaningful” to those who take part in them. For this to be effective, it is essential that those involved in consultations do not feel that decisions have been made before the consultation has taken place. Adequate time must be allowed for the process, and where possible, consultations should not take place over holiday periods (summer and Christmas holiday times) when deadlines cannot easily be met.

   In addition, people who have contributed to consultations should receive feedback so they know the outcome of their involvement.

4. **Local accountability**

   Although this is not an area for comment, the meetings the forum has attended stress the need for local accountability. There appears to be no firm idea on how this will work in practice. It would be a great mistake to allow the work of the last three years and the relationships built, by forums with various Trusts, groups and networks to be lost and the forum would urge that this good work be recognised.

   Obviously the host organisation will be accountable to the Local Authority in its delivery of the contract. The LINk, however needs to be accountable in a different way and would suggest that in the same way as membership and appointment of membership is governed by the constitutional arrangements of the host organisation. This could also work in terms of accountability of LINks to the community. Membership of the LINks would be open to community and voluntary organisations and individuals. The host organisation should open the membership as widely as possible and their accountability would come through the membership. This would happen through Annual General meetings and other meetings of the membership.

   **North Tynside PPI Forum**

   **3 January 2007**

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**Evidence submitted by the Northern Group of Oxfordshire PCT PPI Forum (PPI 65)**

1. **Why are PPI Forums being reformed after three years?**

   The DoH has offered very little information about what they think has gone wrong with Forums, however it was the DoH which killed off the Community Health Councils and we wonder if the same kind of chop and change policy is being repeated for the sake of being seen to be doing something—anything! The DoH has also given very little information out about why it thinks LINks will be better than either the CHCs or the PPIFs, and how they see the LINks system functioning and achieving MORE than the PPI Forum system is currently achieving. (Will they make the same mistake as with PPIFs, ie lack of training of inexperienced members of the public who became Members of Forums. As a result of the badly-planned set-up period, the Forums have had a sharp learning curve but now appear to us to be working well). When considering the track record of the DoH for forward projections of staff requirements, funding, etc., and knowledge of the complex relationships of NHS services, we have doubts about the preparations made for LINks. If the DoH can so badly miscalculate, for example, the financial effects of the new Consultants and GPs contracts and the costs of the EC Directive on Working Hours (an error factor of perhaps £30 million in total in Oxfordshire alone), who would rely on their forecast of the efficacy of LINks?

2. **Violent change requires time to bed down**

   The DoH has a penchant for (a) springing surprise changes on the NHS and its auxiliary bodies without sufficient consultation and (b) not giving any new system time to bed down. If there were fewer radical changes and more consultation, the changes would be more beneficial, less violently revolutionary and have a greater chance of successful implementation. It is therefore difficult for the existing Forums to know what the final structure and operations of LINks will be. How can we comment constructively on what is basically a vague concept?

3. **Adequate funding required**

   The lack of funds trickling down to PPI Forums has been a major setback for Forums and this must not happen to LINks. Very little advertising has been done by the CPPHI or DoH to recruit Forum Members or to keep NHS staff informed of the activities (or even existence) of Forums at a local level. Public awareness is still not good after three years of existence. We also need funds for training programmes (we have found the CPPHI training courses inadequate for our needs) and Member/team development. Of even greater importance is funding for patient and public opinion surveys on local NHS services (including printing of information leaflets and news releases/photos). If LINks fares the same way we confidently expect that
LINks will also “fail” (if we have failed!). It has been strongly rumoured that the DoH was not enthusiastic about the form PPI took when it was launched, which was probably due to inadequate consultation and parliamentary timetabling, but went ahead with the scheme rather than pull out at the last minute. We have no direct knowledge of whether this is true.

4. **How should LINks be designed?**

We are dubious about the internal stresses likely to be in-built into LINks with the close connections between Overview and Scrutiny Committees, local branches of pro-active national charities with professional staff at local level, and the entirely voluntary/altruistic PPI Forum Members who are essentially men-and-women-in-the-street. Local politicians and professional charity staff will have both hidden and open agendas and an element of self-interest and conflict of interest. This will vary from area to area. It is difficult to see why a high-powered charity would wish to recruit volunteers for a “sedentary” organisation such as LINks when it is already desperately short of volunteers for its own activities. We are particularly concerned about relationships between OSCs and Social Services departments and the potential for conflicts of interest, and between them and charities who act as service providers, all of which may have representatives on the local LINks.

5. **Local and national**

PPI Forums are currently cooperating nationally and regionally on a variety of patient-orientated projects. We feel that it this is probably a unique democratic process in the NHS which is unlikely to be matched, let alone bettered, by LINks. Apart from this, LINks should be purely local in operation and not organised nationally. Overlap between the activities of OSCs and LINks is a positive factor.

*Christopher Ringwood*
Chair, Northern Group of Oxfordshire PCT PPI Forum

*9 January 2007*

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**Evidence submitted by Oxford Radcliffe Hospitals NHS Trust PPI Forum (PPI 46)**

*What is the purpose of patient and public involvement?*

To ensure that the NHS is patient-centred. Specifically, to determine that existing conditions and future developments are influenced by the concerns and wishes of patients and the public.

*What form of patient and public involvement is desirable, practical and offers good value for money?*

Ideally, patient and public involvement should represent the whole community, but in practice, volunteers tend to be those who are free to attend meetings and conduct inspections during working hours. We believe this is acceptable, on the condition that the volunteers report regularly to the public and act on issues presented to them by patients and the public. Unpaid volunteers offer the best value for money, but it would help to curb expenditure if each group of volunteers were allocated a fixed budget to cover expenses, such as travel and parking costs.

*Why are existing systems for patient and public involvement being reformed after only three years?*

We assume that Government believes the current arrangements to be unsatisfactory. This is not our view, or our experience.

How should LINks be designed, including:

- Remit and level of independence.
- Membership and appointments.
- Funding and support.
- Area of focus.
- Statutory powers.
- Relations with local health Trusts.
- National coordination.
We believe there are compelling reasons why LINks should mirror the remit and level of independence currently awarded to PPI Forums. Unless members of LINks are truly independent of party politics and NHS allegiances, the value of their contribution will be biased. We believe that the following should be maintained:

— Statutory rights for information within 20 working days.
— Powers of entry to NHS premises.
— Powers to monitor and inspect premises where NHS patients are treated.
— Independence.
— Specialist groups as at present, e.g., Acute Trusts, Ambulance, Mental Health etc. Individuals cannot be expected to cover the whole range of NHS services; people are more effective if they have the opportunity to learn how a particular aspect of the NHS functions.
— Appointment of individuals should continue to be strictly regulated, e.g., CRB clearance.

How should LINks relate to and avoid overlap with:

— Local Authority structures including Overview and Scrutiny Committees.
— Foundation Trust boards and Members Councils.
— Inspectorates including the Healthcare Commission.
— Formal and informal complaints procedures.

1. Both LINks and Overview and Scrutiny Committees should provide each other with quarterly reports on activities.

2. Foundation Trust boards and Members Councils should be required to have one member who is also a member of LINks. This should not preclude the appointment of additional LINks members if the body concerned wishes to make such appointments.

3. There should be a strong relationship between LINks and the Commission for Patient and Public Involvement in Health (CPPIH). As a Forum, we would prefer any new arrangement to be managed by the existing CPPIH.

4. Subject to issues of patient confidentiality, the NHS should be required to submit reports on complaints to the relevant LINks.

In what circumstances should wider public consultation be carried out and what form should this take?

We believe sufficient public consultation has taken place, and we fear that Forum members will lose commitment and enthusiasm unless the new arrangements are agreed upon soon.

Finally, we would like to contribute the following:

(a) Patient Forums have made a valuable contribution to the NHS since they were formed (see CPPIH Annual Report 2005–2006: National Summary).

(b) Hospital Trusts are now required to listen to the views of the public on health issues.

This is progress, and it is vital that any new arrangement provides for a continuation of existing good work. The NHS, by legislation, must be required to co-operate with LINks and demonstrate in their submission to the Annual Health Check that they have responded positively to comments/recommendations made by the public.

Oxford Radcliffe Hospitals NHS Trust PPI Forum

January 2007

Evidence submitted by the Oxfordshire Locality Group of the Mental Health (Oxon and Bucks) PPI Forum (PPI 71)

I write to submit evidence to the Health Committee on behalf of the Oxfordshire Locality Group of the Patient and Public Involvement Forum (PPIF) for Mental Health (Oxon and Bucks).

From the inception of the Forum system until May 2006, this group was an independent Forum but was reorganized to be part of the Oxon and Bucks Forum following the bringing together, for reasons of efficiency, of the Oxfordshire and Buckinghamshire Mental Health Trusts in April 2006. This joint Trust is now applying for Foundation Trust status. Because of underlying diversity of locality, policy and performance, including financial, much of the work of the matching Forum is still organized on a county basis. The basis of our evidence is therefore three years of visits, discussions, and attendance at meetings with an ever-growing number of groups, institutions and NHS, social services and local political organizations such as the Overview and Scrutiny Committees of both Oxford City and Oxfordshire.
Within our own specific responsibilities, we have already developed ways of working comparable with those suggested as necessary to the new LINks on a more general basis. Our main contention is that from our experience, mental health is unlikely to be adequately served within the admittedly sketchy outlines of the LINks. We can provide details of our programmes and findings, if these would be of interest and we would be prepared to give oral evidence if this would be of use.

1. This paper seeks to draw the attention of the Committee to various reasons for considering the particular needs of mental health as something of a special case when setting up the new LINks arrangements. Although as a PPIF we have sought to work with the Primary Care Trusts for Oxfordshire—previously five but now only one—we do not consider that this co-operative approach has been able to produce adequate evidence from patients, carers and public about the needs of mental health as a whole. The Mental Health Trusts are concerned only with the most acute needs of the mentally ill, both in hospital and in the community. Particularly now that orthodoxy increasingly requires treatment in the community, more and more provision falls to be made by the Primary Care Trusts, where mental health competes with the full range of medical needs for the limited funds available. Patients moving out of the care of the Mental Health Trusts can become much less visible as they move into this less well-informed highly competitive primary care environment. In addition they may find themselves disadvantaged in their claim on social services budgets for housing and other provision, such as in day centres or further education. Largely unseen, carers are being expected to shoulder increasing burdens. The NHS care of such patients can be too little or too late, leading to their early return to the care of the acute services. The funding of patient paths for the mentally ill has been no-one’s overall concern. Technically the LINks should provide a better environment for this but attitudes are going to have to change so much for mental health to get its fair share that we think it is essential that under the new dispensation there is the equivalent of a single PPIF which will embrace the whole range of mental health care, wherever provided, its standards and financing.

2. A particular difficulty for the care of mentally ill patients in Oxfordshire is that the top of the pyramid is the joint Oxfordshire and Buckinghamshire Mental Health Trust, which is dependent for the commissioning of its services and for the parallel provisions, in Primary Care and Local Authority Social and Community Services, on two very different county providers. On present showing, the availability of funding from Buckinghamshire cannot be counted upon, and attitudes also differ. In any case, despite the Government’s having identified mental health as a priority, neither county has been in much of a position to honour this. For the joint Trust’s future efficiency and parity in its provision, it needs to be negotiating with a single body.

3. Certainly in Oxfordshire, the Mental Health Trust has been discriminated against in so far as it was required, mid year, to make substantial cuts in its budget so as to help less well performing parts of the local health economy, despite having broken even for the last three years and having a unit cost below the national average. When the PPIF attempted to discuss the implications of this for patients and carers with the relevant PCT and the Commissioners, we were told that the demonstrable needs of mental health patients could not stand against the claims of patients, say, with varicose veins—for whom there was an unmet target—or of those waiting for cochlear implants. There seemed to be no appreciation of the potential waste of life—in any sense of the term—associated with inadequate care for the mentally ill, many of whom—if one has to talk in such crude terms—have a great deal to offer both the community and the economy. And, of course, for the increasing number of patients over the age of 65, that economic argument cannot be invoked and, despite the new rules against ageism, their claims on available funding become vulnerable.

4. There is, in fact, a double problem in the commissioning of provision for mental health: firstly, because many people misunderstand its nature and rather write off those who are mentally ill, it cannot compete on equal terms with the more familiar illnesses with recognized prognoses; and secondly, in a group of commissioners and expert advisers there may be only one—or sometimes not even that—to speak up for those representing other strongly defined medical interests. When our PPIF suggested to the lead PCT that the funding might become more equitable if there were more specific targets for mental health, we were told that would never do because it might mean reduction in more ‘popular’ targets. If the new LINks specifically concentrate on commissioning, this problem is bound to be looked at, but it will be vital that the many but coherent claims of mental health are strongly established and properly supported. It is hard to see the necessary expertise being widely available in practice-based commissioning and it is not clear that special groups interested in mental health but drawn from such general bodies as the new LINks could really be the answer.

5. It is important to stress at this stage that Oxfordshire, as one might expect, has never been short of articulate voices making the claims for mental health as for any other medical condition. Furthermore the Mental Health Trust tries, within the limits of financial and procedural constraints, to keep itself informed of local opinion, both in general and in the context of any specific problem. The Trust has standing committees of users and carers but a reading of the minutes shows how limited and almost ritual the exchanges are. It also meets regularly with a Task Force formed from the main Voluntary Bodies but again the minutes show that, however productive, these meetings do not constitute anything like the rosy picture envisaged in the LINks proposals. And there are many more voluntary bodies and lobbies, not least those concerned with ethnic minority groups, which are not part of this rather stage army. Our PPIF would be
the first to admit that we cannot hear and listen to as many voices as we should. This is going to be a massive problem for the LINks in general but, when one thinks what is likely to be the limited representation of mental health issues, it is hard to see that the mental health voice will be any stronger or more reliable.

6. It is vital that the patient and public voice that is heard is based on absolutely up-to-date evidence from as wide a range of all those concerned as possible. We understand that, contrary to the original proposal, LINks will retain the right of direct scrutiny provided by visits. In addition it is said that they will arrange for surveys and the like. Surveys take time to organize and process, and the necessary skills to design them so that they get to the full facts are not in great supply. The use of open questions is understandably rare. It is often difficult to achieve a reasonable return or to have any understanding of the position of those who do not respond. We have looked at questionnaires used both locally and nationally and have to say that in some cases, on the evidence of our visits, the questions asked are not the right ones—though admittedly they make box-ticking easy. We also recognize that getting patients, carers or staff within the mental health system to answer honestly is difficult. Patients and carers often lack the confidence to record their real perceptions, more so than the average NHS user. Facts and views collected on visits, though they risk having been solicited by leading questions or being the result of over strong personal conditions, can provide a much fuller view of reality.

7. Certainly our very wide programme of visits has shown that under the pressures of ‘reconfiguration’, the Trust’s admirable policy statements cannot always be implemented on the ground and that big financial efficiencies are obscuring the loss of some small services which make such a difference to patients’ recovery. We are clear that improving the provision for mental health patients is not only a case of improving funding arrangements but also of ensuring the best possible day to day environment for patients within existing expenditure. This requires a great deal of training for staff and the release of professional time to improve the interface between professional and patient. How the LINks will be able to deal with this is difficult to see, but deal with this they must.

8. There are other points we could make where mental health very obviously shares problems common to a great deal of NHS provision. Transport and protected housing are examples. There is a whole new world to be explored in terms of local authority budgeting, including the relationship with the Treasury. But the importance of both to the successful care of vulnerable mentally ill patients cannot be sufficiently stressed. The problem is again how to secure enough provision for mental health in the general world of bargaining and compromise within restricted financial resources and centralized policies.

9. We do not at this stage wish to comment on the suggested need for LINks to form up into some national opinion making body. In our view the lessons of dealing with the unavoidable complexities of the situation are best learnt thoroughly at the local level.

Ben Lloyd-Shogbesan
Co-chair, PPI Forum for Mental Health (Oxon & Bucks)
8 January 2007

Evidence submitted by Oxford and Bucks Area of South Central Ambulance Service PPI Forum (PPI 135)

Future of Patient & Public Involvement and LINks with particular reference to Ambulance Patients Forums

I am Eileen Young—Chairman of the Oxford & Bucks Area of South Central Ambulance Service Patient & Public Involvement Forum.

1. It is outrageous that PPI Forums should be abolished after only two years and that the Government has been aided/abetted in this by collusion with the “Panel of Experts” chaired by Harry Cayton in Spring 2006 which concluded that Patient Forums had been a failure. So, on 12 July 2006 the DoH publishes the ridiculous, airy-fairy document—A Stronger Local Voice—for information & comment only. Not a consultation! This was not intended to be circulated to PPIFs, CPPIH or indeed, Local Authority OSCs for Health.

2. LINks? What on earth are they? Obviously someone at the DoH came up with this acronym and the Department now hopes someone—will tell them how to design a system around it. Now the Government has pulled a really fast one. Need to legislate to get rid of CPPIH & PPIFs? Simple—slip it into the good old Local Government (Public Involvement in Health) Bill 2006–07. First reading before Christmas, 2nd one next week; well on its way already.

3. Anyway, I attended yet another DHN event this week on 9 January where Dr Richard Taylor MP gave an excellent exposition as to why those two “weaselly” clauses in the Bill—to abolish PPIH & set up the framework for development of a LINks system (?)—will not be opposed because the rest of the Bill is uncontroversial.
4. We members of the South Central Ambulance Service Patients & Public Involvement Forum are having a hard time trying to work out how on earth we can relate to our Overview & Scrutiny for Health Committees of the local authorities in our “patch”. Our patch covers the area from Southampton/Portsmouth up to Milton Keynes and consists of four County Authorities and nine Unitaries.

Our Forum Support Officer took the initiative and organised a meeting in Newbury on 5 December 2006, inviting all 13 Overview and Scrutiny Committees to send representatives. Chairmen and Officers from nine authorities attended a very useful meeting but it was clear at the end that the OSC folks did not understand what they will be taking on when “LINks” arrive at their door and they certainly have no comprehension as how the SCAS—PPIF (21 of us at present and 1.5 Forum Support Officers) can possibly be expected to “LINK” to so many and over so huge a geographic area?

5. I did challenge Dr Taylor on this aspect of what is about to happen. All we do know about LINks so far seems to be that it could consist of “up to 1000 people in an area, getting together over a local health issue” (Meredith Vivian, DoH).

6. This whole thing just gets more and more weird. Please do something to alert MPs and drum up some opposition to this ludicrous “airy-fairy” notion of LINks and make the DoH, or whoever, go back to the drawing board and, at least, draw up an outline of a scheme; including how it will be run, financed, resourced and by who. We were told, at the DHN seminar earlier this week, that the pilots being set up at present in 6 areas across England have been given no money, no “brief” and no resources to begin work.

Eileen Young
Chairman of Oxon & Bucks PPI Forum, South Central Ambulance Service
11 January 2007

Evidence submitted by the Parkinson's Disease Society (PPI 1200)

1. The Parkinson’s Disease Society (PDS) believes that enhancing the voice of the patient in service planning must be at the centre of patient and public involvement in the NHS. People with Parkinson’s are often the most knowledgeable about their own condition and how it affects them, and have a valuable contribution to make in working with the NHS and local authorities to improve the quality and efficiency of local services.

1.2 The PDS welcomes proposals to establish local involvement networks (LINks) for every council with social care responsibilities. This has the potential to deliver more integrated health and social care services.

1.3 The PDS welcomes moves to increase co-terminosity with Local Authority boundaries. This is greatly in the interest of people with Parkinson’s as, through the course of their condition, they will have varied and interrelated health and social care needs, for example, palliative care and carers support.

1.4 The PDS has some 30,000 members and more than 300 local branches and support groups who are very keen to engage in the local decision making process. Many people with Parkinson’s around the country are actively involved in PPI forums.

Patient and Public Involvement Project (PPI Project)

1.5 The Parkinson’s Disease Society has worked to increase the influence of people affected by Parkinson’s on health and social care services. In 2003 the Department of Health supported the PDS with a Section 64 Grant to support branches and groups to become involved in and influence local health and social care services.

1.6 Since then the Parkinson’s “Patient and Public Involvement Project” (PPI Project) has worked with PDS branches, support groups and individuals in pilot projects to help them influence health and social care planning. The PPI Project has identified resources that can support people affected by Parkinson’s to be more effective in making their views about health care known and influencing planning, services and policy.

1.7 The PPI Project involved six pilots across England and these pilots identified the important factors crucial for successful patient involvement in local health services. Below are two case studies which provide useful evidence of good practice.

PPI Case Study—Carers Experiences in the South West Pilot (Avon, Gloucestershire and Wiltshire)

1.8 One pilot project in the South West, which involved branches of the PDS and groups of volunteers, set out to give carers of people with Parkinson’s a voice in the development of home care services. This involved semi-structured interviews and group meetings, culminating in a report about carers’ experiences which formed the basis for meetings with Local Authority carers officers.
1.9 Facilitating a formal dialogue between carers of people with Parkinson’s, PDS volunteers and PDS branch members increased awareness of local authority support to carers. Local Authority officials were in turn made more aware of Parkinson’s and the PDS. The personal experience of Parkinson’s amongst Branch volunteers was valued by carers who took part in the pilot.

2. One PDS Volunteer Who Took Part in the Pilot said:

“We were unsure about our abilities to do this but we found the common spine for one-to-one interviews straightforward. Sharing the work so that one of us took notes and the other managed the interview was essential. In each interview we were struck by recent improvements in support available for carers but also how isolated and vulnerable people who care for someone with Parkinson’s can be. It was hard not to want to step in and try to change things, and where we could provide information or signposts to support we were glad to do that. The project has encouraged us to address other issues and may have provided a foundation for other work next year.”

PPI Case Study—Depression and Parkinson’s (Avon, Gloucestershire and Wiltshire)

2.1 This pilot, undertaken by the Cirencester Branch, consulted people with Parkinson’s and their carers in order to ascertain the incidence of depression amongst people with Parkinson’s and to develop a map of local psychological support services. One aim was to inform local NHS commissioners about the likely level of need for psychological support and to influence local provision of psychological support services.

2.2 Meetings took place between the PCT Patient Advice and Liaison Service (PALS) team and people with Parkinson’s and their carers to discuss how their views and experiences could influence NHS services. The PDS Branch and the NHS Trust were keen to ensure that the project’s design and methods for member consultation were strong enough to influence the NHS.

2.3 Project planning meetings emphasised the need for a structured programme of research using depression scales and inventories, focus groups and individual interviews across the county. The Trust proposed a programme of research led by the lead psychologist, supported by a psychology assistant.

2.4 Volunteers worked hard to develop ideas for the project. They learnt much about how different parts of the NHS took the opportunity to engage with and involve people with Parkinson’s in developing services. However,

— PALS information was helpful but did not recognise the contribution of user-led research to PPI or suggest collaboration with others (for example, the PPI Forum or the local Health Overview and Scrutiny Committee).
— The NHS Trust led the Branch to a sound research proposal but Branch members found they could not engage with it. There was no exploration of the differences between consultation and research for Branch and volunteer engagement.
— Branch members and volunteers felt that the interests of people with Parkinson’s were increasingly lost as the research design grew more complicated.

One PDS Volunteer said:

2.5 “The consultation programme proposed by the NHS Trust was daunting for members and volunteers. Most felt that they would gain little from such a large commitment. There were other, simpler, ways of collecting views and experiences that would have informed NHS services.”

Lessons to Learn from the PPI Pilots

2.6 These pilots illustrate the important factors to take into account when planning for successful public involvement in developing health and social care services:

— The expertise and resources of the voluntary sector should be harnessed when consulting the users of health and social care services.
— Carers and PDS volunteers with experience of Parkinson’s should be valued for their insight, sensitivity and practical knowledge about the effect of Parkinson’s and the delivery of health and social services.
— PDS staff are well placed to mobilise and sustain volunteer effort to influence local services by providing information, guidance and support.
— Branches and voluntary groups are more likely to sustain involvement and influence over time when they can work together on issues and share resources.
— PALS must support branches and groups in making their members’ views known and by signposting local voluntary groups and patient involvement initiatives.
— Public sector funds should be available to support involvement—from travel expenses to meeting costs.
— A variety of methods should be used to gather different views, experiences and perspectives. These include formal structured interviews, informal discussions, and meetings with NHS and local authority officials.
— User led research makes the most of experiences and interests.
— Health and social care staff must actively support alliances and partnerships who respond to consultation opportunities. NHS services (especially PALS) ought to put people in touch with groups that can help them both present their views and define effective ways of collecting and presenting others’ views.
— NHS and LA databases of organisations interested in consultation and involvement around relevant services (including neurology, carers support, older people, psychological therapies, access to allied health professionals and therapies) should include information about local PDS branches.
— Local “maps” of NHS and LA structures and systems should be freely available and proactively provided for all branches, groups and volunteers so that they can target information and influence effectively.
— Administrative and analytical support for volunteers involved in collecting people’s views and influencing services, including arranging meetings, collating and analysing policies and practices and producing reports, should be provided by the new LINks.
— Feedback must be provided to those consulted.
— The nature and impact of Parkinson’s on an individual’s involvement must be taken into account.

2.7 Design of LINks
— The PDS believe that existing PPI Forum Chairs and members should be invited by local authorities to meetings in order to discuss future arrangements and an effective transition.
— The PDS believe that the Department of Health must ensure that patients are not left in a vacuum during the transition between PPI Forums and LINks, as they were between the demise of Community Health Councils and PPI Forums becoming effective.
— The close links that existing PPI Forums have with the Patient Advice and Liaison Services (PALS) must be maintained. As illustrated in the PPI project pilots, PALS are vital for patients currently using services provided by the local Trust and are one of the many services PPI Forums link with.
— At a time when local authorities are reported to be over £1.7 billion in debt (Association of Directors of Social Services 15/03/06), the PDS believe it will be important that LINks are properly funded, to ensure they apply equally across the country. The PDS believe it is essential that the budget for LINKs, paid to local authorities by central government, is ring-fenced.
— With the current changes to the NHS currently taking place, the PDS believe that it is more vital than ever that existing PPI Forums remain active in providing the voice of the patient in local decisions.

2.8 Voluntary and Community Sector
— It is encouraging that local voluntary and community groups will be invited to become members of LINks. The PDS welcomes the recognition of the important role that such groups can play in promoting community influence in health and social care.
— Many members of the PDS are members of existing PPI Forums. The PDS urge the Department of Health to ensure that local community groups and voluntary organisations are aware of the changes that are being made and the opportunities to get involved in future LINks.

2.9 Attracting members of LINks
— Recruitment of members to a LINk must be open, and focused on creating a diverse and effective network, drawing on expertise from both the health and social care sector.
— The NHS Appointments Commission is the expert body that was set up to make public appointments, so it is logical that recruitment on the scale necessary to maintain forum numbers is carried out by an organisation that is expert in making appointments. However, the PDS believe that this could place the emphasis on health rather than social care. The Association of Directors of Social Services must also be involved in the process of recruiting members to LINks.
3. Governance Arrangements for LINks

— The PDS does not support the idea of a specific body, such as the Commission for Patient and Public Involvement, being set up to recruit members, fund and oversee LINks. Resources must be channelled directly to support LINk activity and, as noted above, should be ring-fenced.

— Each LINk should be led and controlled by an effective Board of trustees who must ensure that the network upholds and applies the principles of equality and diversity, so that it is fair and open to all sections of the community in all of its activities.

— Patient Public Involvement Forums currently have statutory rights to enter and inspect NHS premises. The PDS believe it is essential that the same rights be given to LINks.

— Overview Scrutiny Committees often use PPI inspection reports as evidence in their reviews. Involvement of lay people in inspections by the CSCI is not a substitute for loss of local inspection rights. If LINks are to provide OSCs and PCTs with information, without inspection rights the quality of this information and its breadth are limited.

3.1 Response of Commissioners

— The PDS welcomes the idea of PCTs developing a framework for reporting on commissioning policies in the form of a prospectus.

— A Stronger Local Voice suggests that the main focus for Overview Scrutiny Committees should be the commissioning process through which local services are shaped. The PDS welcomes the proposal that OSCs will have to respond to referrals from LINks. A strong working relationship with their local LINK is therefore essential.

— Plans for PCTs to formally respond to public petitions, if more than one% of the local community are unhappy with a particular service, are welcomed by the PDS.

3.2 Host organisation to run a LINk

— The contract with the local authority must strike an equal balance between health and social care, so that the host organisation is able to develop expertise in both areas.

— The host organisation should be in a position of financial stability and committed to the values of diversity and inclusion. The PDS believe that knowledge of the impact of long term conditions and an understanding of good quality associated services would be an advantage.

3.3 The Parkinson’s Disease Society

The Parkinson’s Disease Society (PDS) was established in 1969 and now has 30,000 members and over 300 local branches and support groups throughout the UK. The Society provides support, advice and information to people with Parkinson’s, their carers, families and friends, and information and professional development opportunities to health and social services professionals involved in their management and care.

Nicholas Bungay
Parkinson’s Disease Society

10 January 2007

Evidence submitted by Patient Opinion (PPI 88)

Background

1. Patient Opinion is a not-for-profit social enterprise which was established in 2005 by Dr Paul Hodgkin, a Sheffield GP.

2. This submission is informed by our experience over the past two years in developing an innovative web-based approach to patient and public involvement in health services.

3. Because of this particular experience, we address here only two of the questions posed by the committee/those for which we believe we can bring a new perspective to PPI.
What is the purpose of patient and public involvement?

4. Very broadly, there are two important purposes to PPI. The first relates to issues of accountability, democratic engagement in public services, and social capital (and possibly therefore health and wellbeing) generated by an active and engaged citizenry. Others will have far more to say on this than we are able.

5. The second purpose, which is at the centre of our work, is the belief that patients’ experiences of using health care provide both the information and the motivation which is fundamental to improving health care. The importance of customer experience has been understood for many years in the commercial sector, but only recently in public services.

What form of patient and public involvement is desirable, practical and offers good value for money?

6. The central point which we wish to make in this submission is that the new forms of social engagement, participation and collective action are emerging, based either wholly or partly on the web, which have much to offer in developing new approaches to PPI which are widely accessible, inherently democratic, flexible, scalable, timely and highly affordable.

7. Harnessing the power of the web in the cause of PPI brings both advantages and disadvantages. We do not suggest that web-based approaches could ever entirely replace traditional forms of public involvement. But we do suggest that the possibilities offered by the web are so great that to ignore the role it can play would be folly.

8. The strengths and weakness of the web are well known. In the context of PPI, perhaps the key benefits of web-based approaches are convenience and accessibility (especially for patients and carers unable to attend public meetings), scalability to large numbers of participants at low cost, and an essential egalitarianism which means that even the quietest voice counts as much as the loudest.

9. Among the disadvantages, in this context, are the unfamiliarity of the web to many people, the fact that access is not yet universal, and the lack of face-to-face interaction which means that establishing authenticity and trust may be problematic. But these problems are not insurmountable, and will in any case decrease with time (and perhaps much more rapidly than we imagine).

Patient Opinion: harnessing the web for PPI

10. Patient Opinion has created a web-based platform for patient feedback about health services. Our current service launched across England in January 2006, and allows patients, carers or relatives to contribute opinions and ratings about inpatient or outpatient hospital care. We aim to cover mental health care, maternity care and primary care in 2007/8.

11. We aim to tag all feedback with the relevant hospital and specialty to enable accessibility. We review all feedback prior to publication on the Patient Opinion web site (www.patientopinion.org.uk). On publication, all feedback is immediately and freely accessible for public benefit.

12. We offer reporting, response and data feed services to healthcare organisations to enable them to engage more strongly with patient views, benchmark their patient reputations against others, and ultimately become more patient-focused in their everyday work. This is the source of the income required to sustain and develop the service.

13. Feedback can be routed, by email, from the patient directly to the health service manager responsible. Health services are able to respond to feedback online to show what they are doing in response to feedback.

Lessons from Patient Opinion to date

14. We have demonstrated through our existing service that the web offers a practical, affordable approach to enabling patient feedback about health care.

15. The directness and rawness of patient stories on the web gives them real power to produce change. This directness stands in sharp contrast to the complexity and opaqueness of many existing and proposed PPI structures.

16. The public nature of the feedback we publish adds to the pressure for change. It also makes patient experience a national resource which can be easily accessed by anyone to inform local, regional or national debate about the quality health care in specific places, or for specific conditions.

17. Healthcare commissioners, elected representatives, LINKS, PALS, scrutiny committees and others can make use of, and in some cases respond to, this patient feedback.

18. Healthcare providers are initially cautious about engaging with Patient Opinion. However, we have found that where they do engage, they begin to make small but significant service changes in response to patient experiences and suggestions. We are able to share specific examples of such change.
19. For the sake of brevity, this submission has described the existing Patient Opinion platform, development plans and lessons to date only in outline form. There is much more to say than can be included here.

20. Accordingly, we would be very glad to provide further information or share more of the lessons from Patient Opinion, either in written or verbal form, if the committee would find it relevant.

Dr Paul Hodgkin
Chief Executive, Patient Opinion
January 2007

Evidence submitted by London Ambulance Service Patients’ Forum (PPI 78)

1. INTRODUCTION

The Patients’ Forum for the LAS is a pan London forum which has operated successfully for three years with a membership of 15. It is highly successful as an advocate for communities across London and is leading the way on many public health issues. Abolition of the Forum is in our view highly destructive because it will destroy three years of creative work. Most importantly abolition will dismantle the establishment of successful relationships between the Forum and many community and voluntary organisations and between the Forum, the LAS, London’s 32 PCTs, MPs, the Strategic Health Authority and many other organisations across London.

The Forum believes that the relationships developed with all parts of the LAS have enabled us to operate effectively as an agent of influence on the quality of services provided to Londoners. It would take years for LINks to build a pan-London organisation with the level of expertise and influence which has been developed by the Forum—should LINks choose to do so.

In our view closing a Forum with such highly successful and acclaimed record of PPI with the LAS is irrational.

2. What is the purpose of patient and public involvement?

The Forum believes that the primary purpose of PPI is to enable patients and the public to be able to influence local health policy and the delivery of services. We include commissioning within health policy. PPI offers a way for the public to find a way through the highly complex health bureaucracy which confronts the citizen when he or she tries to exercise influence in the NHS. There is a distinction between the role of citizen in suggesting change through PALS which sometimes works well, and the longer job of sitting with policy makers and planners to steer policy and planning towards the needs of a community. PPI provides a public voice for the community, which is especially important in organisations that undergo reorganisation so often.

PPI is much more than “patient and public engagement”, it should be about empowerment. The Government’s commitment to revitalising community empowerment across the broad range of public services, cannot be realised by the powerless, ineffective bodies suggested by the creation of LINks. Indeed, it could be argued that the LINks proposals are more accurately a means of disempowerment, unlikely to achieve the aim of enabling citizens to become active partners in their healthcare and will not help create a system where people are no longer passive recipients or better equipped to make decisions about healthcare in their community.

3. What form of patient and public involvement is desirable, practical and offers good value for money?

There are many excellent examples of successful patient involvement and empowerment over the past 32 years of PPI in the NHS, where citizens and service users have genuinely influenced their local services.

We would recommend local independent councils of elected citizen working closely with the voluntary and community sector and resourced sufficiently to be able them to have a well recognised public role and profile. Local high street offices where members of the public and community groups can meet to discuss and plan developments in health policy, campaigning and where various forms of advocacy can be provided at an individual and community level.

For mental health and ambulance services a hub and spoke model so that bodies can monitor large trusts and link in closely with local PPI organisations.

Supported by small local expert teams with a centralised infrastructure for HR etc. This requires a recognised training scheme to ensure that team members are professionals in PPI and can support members effectively.
Funding of the new system is a key issue. In the current system funding is denied to the front line where real PPI takes place. This Forum cannot even get money to fund a professionally produced annual report. Funding must be adequate for the task of genuine PPI, must be sufficient to find sufficient numbers of highly trained and professional staff to support members. Finances must be in the control of members.

4. Why are existing systems for patient and public involvement being reformed after only 3 years?

Because they lack sufficient powers to exercise local influence and are dependant on a weak and confused national bureaucracy, which has commissioned local FSOs which have often been incompetent.

Destroying PPI infrastructure for a second time in three years will alienate those who are currently involved and is unlikely to attract many new enthusiasts for the powerless LINks bodies. The Department has alienated many people in the community through their systematic destruction of PPI and local communities are unlikely to want to play an active part in a new body that gives far fewer opportunities for PPI than the current PPI structures.

5. How should LINks be designed, including:

5.1 Remit and level of independence

Although Ministers promote the idea of a new LINks organisation based on “independence, engagement, accountability and transparency”, there is nothing in the proposals to show what would be different about LINks that would achieve this aspiration. Indeed it is suggested that the new arrangement are tied to and would be controlled to low volume service providers, whose record on accountability and transparency is sometimes less impressive than that of the NHS.

Although the proposals suggest that a broad spectrum of people would be enabled to influence how their local services are designed and delivered, it is more likely that these proposal will create a conflict of interest that will severely damage PPI. This is because the organisations in the voluntary sector which are expected to be involved in running the new arrangements could well be in competition for service contracts with the NHS and will therefore have an “interest” in commissioning based on their own organisational objectives. The LINks proposal is consistent with the Government’s objective of contracting out NHS services to the independent sector, rather than with increased democracy for the community. In the absence of real independence LINks would be unable to function effectively. Experience has repeatedly shown that community groups working in the health field without independence real powers get sucked into the social infrastructure of the NHS and lose the ability to function effectively.

5.2 Membership and appointments

Membership should be locally elected and not selected through an NHS appointments body. A strategy is required to ensure that over time all sections of the community are involved. Active support and training will be required to involve individuals and groups that have had no previous experience of working with health policy, monitoring and commissioning.

5.3 Statutory powers

Since 2003, statutory powers held on behalf of the community have substantially diluted, in fact the Patient’s Forum legislation is devoid of any duty on NHS to consult Patients’ Forums. The powers granted to Patients’ Forum are also devoid of the most important power ever to be exercised by communities in relation to the NHS, ie the right challenge closures and changes of use NHS services. The absence of any statutory powers that give the community a “seat at the table” by right in discussions and negotiations about the future of local services has substantially weakened the capacity of communities through their Forums to exercise real influence in the NHS.

With the abolition of Forums, communities, patients, users and carers will lose most of their remaining powers. The right to monitor the NHS will no longer rest with the Forum, but will be transferred to the NHS body as a duty to allow access to Forums in order to observe activities in the Trust. The power to inspect premises on behalf of the community will effectively be lost.

Working with powerful PCTs, NHS Trusts and Foundation Trust requires more than a “grace and favour” relationship between LINks and the NHS body. To exercise real influence and to be taken seriously will require LINks to have the statutory power to monitor the NHS, to veto decisions which are not in the best interests of the local community, to influence commissioning decisions and to call on those accountable for decisions in the local NHS both in terms of services and commissioning to account for their actions.

LINks also require statutory power to monitor non-NHS providers and commissioners of services (should commissioning funds pass to non-NHS groups or bodies) and to call them to account.

Rather than developing health and social care services that are user-centred, responsive, open to challenge and accountable to communities, Ministers appear to be weakening the opportunity for PPI to have any real impact. Empowering citizens through LINks with appropriate statutory powers would also give them more confidence and more opportunities to influence the effectiveness of public health and preventative services.
The issue of appropriate statutory powers is also of particular importance with respect to the plethora of private providers which are now operating under the NHS umbrella. These bodies have no duties or responsibilities to the public and often refuse to answer questions about the services they offer to patients. Strengthened statutory powers are needed to oblige these companies to operate in the same way as NHS bodies in respect of S11 of the Health and Social Act and other regulations in relation to PPI.

6. Access to Information

It appears that the right of LINks to access information in primary and acute NHS services is no greater than the general rights granted under the Freedom of Information Act.

Access to information is a fundamental requirement for any organisation representing patients and the public in the NHS. Ministers must ensure that such information is available from every part of the NHS and in addition from private provider and not-for-profit providers of services to the NHS.

The right of these companies to use “commercial confidentiality” to prevent the public having information about their services needs to be moderated by Regulation.

Access to information from Ministers is another problem that needs to be resolved for LINks. In the current system questions to Health Ministers from Patient’s Forums are rarely answered by them and instead standard answers from a database are sent by very junior civil servants, who know very little about the NHS and often provide incompetent responses to issues raised by Forum.

7. How should LINks relate to and avoid overlap with:

7.1 Local Authority structures including Overview and Scrutiny Committees

The power to refer matters to the OSCs replicates that of all previous statutory models of PPI. In LINks model however, voluntary sector providers would be able to promote their own services to OSCs with proposals for commissioning that benefited them, and might in some cases be used to harm the NHS as a competitor provider.

The Forum supports the proposal for OSCs to have a role in making sure services are commissioned that reflect the health needs of local populations and that they are reflecting public priorities in the communities. However, as the public has virtually no say in what is commissioned in the NHS, because the NHS is provider driven, the emergence of new weak bodies (LINks) to represent the public’s view and needs in commissioning, is likely to have no impact on high value commissioning decisions, eg the number of hip operation, cardiac bypass and mental health services. OSCs and LINks will need statutory powers to influence commissioning if the current balance of power is to change.

7.2 Foundation Trust boards and Members Councils

Membership of Foundations Trusts appears to have had very little influence on the Trusts. There should be a single powerful system of PPI for every NHS body.

7.3 Formal and informal complaints procedures

Access to ICAS services in the community is extremely poor. They have no public profile and little capacity. The development of LINks provides Ministers with an opportunity to enhance their capacity and community links by relocating the independent complaints advocacy service with local LINks. This was the intention with Patients’ Forums but was never realised. This move would be especially valuable in light of new complaints legislation.

8. In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

Section 11 of the Health and Social Care could be made stronger by requiring PCTs to develop commissioning plans in relation to local need and in partnership with OSCs and LINks. Requiring PCTs merely to respond to OSCs and LINks will not empower the community.

Section 11 is potentially a useful and effective power. However, enforcement for the community is very difficult, because NHS bodies and their suppliers that fail to respond to demands for consultation, can do so without fear of criticism from the DH. The Healthcare Commission should act as an agency of enforcement but fails to do so. A revised Section 11 should ensure that enforcement is available to the community eg through the HCC and the OSC.

In Conclusion:

— The Minister has not shown how the current systems for involving and engaging with patients and citizens will be strengthened and improved by LINks.
— The new system must be properly funded and funding in the hands of front line members, ie patient and the public.
Citizens, patients, users and carers should not be stripped of all the statutory powers that they have been able to exercise since 1974.

Debates with commissioners and providers will not in themselves influence decisions about their health and social care services. LINks would need statutory powers to do this successfully.

The LINks proposals do not make NHS organisations more accountable to their local populations for the services they provide and commission. The only require them to listen and respond.

The proposals will not hold NHS trusts and PCTs more accountable to their local populations.

The commitment to building capacity in voluntary and community organisations will provide support to the voluntary sector as providers, but will not enhance democracy, empowerment or public involvement.

Gathering information from a wide range of people and a wide range of sources about what local people need in terms of both their health and social care will not influence providers and commissioners of services, unless LINks and OSC have powers to require NHS bodies to meet local needs.

Malcolm Alexander
Chair, London Ambulance Service Patients Forum
January 2007

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Evidence submitted by the Patients Forum (PPI 92)

1. About The Patients Forum

1.1 The Patients Forum is an independent network that exists to promote the sharing of ideas, experiences, and information to enable our members to better inform and influence policy developments. We work to improve communication and consultation by engaging with policy developments in a timely way, and by supporting connections between our members and other key stakeholders.

1.2 Our current membership comprises 46 voluntary, citizen and consumer health organisations (full members) and 12 statutory, professional, and academic organisations (associate members).

1.3 We hold six scheduled meetings each year to provide members with the opportunity to come together, exchange information, and to debate new policy developments. In addition, we hold a number of seminars each year on specific issues that our members feel warrant more detailed discussion. We produce a newsletter six times a year to help to facilitate the sharing of information among members, and to identify and highlight key policy developments from a patient, carer and citizen perspective. Patients Forum conferences have been well attended in recent years, with delegates drawn from a wide range of patient, carer and consumer health groups, and statutory and professional bodies.

1.4 In the past, The Patients Forum has also conducted more detailed work on specific areas of interest to our members, for example in commissioning research to examine patient involvement in the development of National Service Frameworks, and work in collaboration with the College of Health and the Long-Term Medical Conditions Alliance on behalf of the Department of Health on the development of a national patient body which contributed to the development of the Government’s patient and public involvement strategy. Patient and public involvement in the NHS has been an issue of ongoing interest to our members.

2. About This Memorandum

2.1 The Patients Forum is not a campaigning organisation. We support, rather than represent, our member organisations and provide a neutral and constructive forum for learning, exchange and debate. This memorandum therefore does not represent the consensus view of our members, but rather is presented as what we hope will be a helpful contribution to the debate.

2.2 Below, we provide some brief thoughts and reflections in response to the questions that the Committee has posed.

3. What is the purpose of patient and public involvement?

3.1 The goal of patient and public involvement in health should be to give service users, carers and citizens a greater stake in the NHS and in the broader components of health that extend beyond the confines of the NHS. It should seek to provide a mechanism for “non professional” perspectives to be expressed, and should increase the accountability of health care to the local community, and to citizens as a whole. In addition, patient and public involvement can also be seen to have a significant role in improving the quality of health care services and support.
4. What form of patient and public involvement is desirable, practical and offers good value for money?

4.1 To be effective, patient and public involvement in health must be able to reach (a) excluded groups, and (b) those who are not currently in direct contact with health care services. Both groups represent a significant challenge for patient and public involvement.

4.2 People who are described as “hard to reach” often fail to get involved in the current structures for patient and public involvement. Creating new structures and mechanisms for involvement that, for instance, requires attendance at meetings or participation on a committee, seems to do little to reach out to these excluded groups.

4.3 Excluded groups frequently require more support and assistance to have their voices heard. For example, one of our member organisations, Sign, the national society for mental health and deafness, has been running a project, funded by the Department of Health, to help deaf and hard of hearing people to get appointed to PPI Forums. As part of this project, Sign provided training to enable potential deaf PPI Forum members to feel that they could make a contribution and indeed should become a PPI forum member. Once appointed the project supports them to become effective. They believe that more support is needed to enable these deaf PPI members to continue to make a contribution and to assist in disseminating the lessons from their experiences. Frequently deaf PPIF members encountered no budgets for interpreters and limited understanding in the forum support organisations of what was required, such as booking communication support for meetings. Ongoing project evaluation has shown that the presence of deaf, hard of hearing and other disabled members on PPIF has helped to raise the issue of deafness/disability awareness in these structures and highlighted the need for reasonable adjustments to be made so to open up the forums to everybody.

4.4 The second group of people—those not currently in direct contact with health care services—also pose a challenge for patient and public involvement. These people may not feel that they have anything to contribute to health care in their community, or may not even see health care as an issue of concern to them at all. It is therefore important for whatever mechanisms are put in place to take steps to reach out to the wider community and to proactively seek to engage people.

4.5 There is also a question over whether it is better to organise patient and public involvement around localities, or around organisations. Some of our members are concerned that the arrangements for the election of governors for Foundation Trusts, for instance, fail to provide a system that is representative of the local community, while purporting to be a more accountable and democratic system than elsewhere in the NHS. Membership of Foundation Trusts is low, resulting in a small, unrepresentative “electorate” which lacks proper accountability to the wider community. Community based mechanisms for patient and public involvement in health therefore appear to be a more attractive option.

5. Why are existing systems for patient and public involvement being reformed after only three years?

5.1 Patients Forum members have been monitoring the development of the Government’s patient and public involvement policy over several years. Some believe that the system put in place under the 2001 legislation failed because of the lack of effective support mechanisms provided to individuals at a local level, and the wide variation in the effectiveness of individual PPI Forums. The lack of adequate investment in patient and public involvement meant that the existing systems were always going to struggle to provide what was expected of them.

5.2 Furthermore, the lack of an effective national voice for patients meant that issues and concerns at a local level had no easy way of being passed up for escalation if needed. This is an essential component of effective patient and public involvement.

5.3 In recent months, The Patients Forum has been working closely with other stakeholders in the voluntary and community sector to explore what sort of “national voice” for patients, service users, carers and the public is needed. This work has been driven by a desire to increase the effectiveness of the patient and citizen voice in the policy making process. Baroness Morgan of Drefelin has been chairing a working group made up of voluntary and community sector organisations to explore how there could be a more systematic approach to involving patients, service users and the public in policy development. That group has been working to agree the principles that should underpin the development of an independent national voice for service users, patients and carers to influence policy across health and social care, and to investigate options to establish a mechanism that represents that independent national voice. In the past few months, the group has been testing a proposition with the wider voluntary and community sector to refine the proposal that it has been developing.

5.4 Although the work of this group is being driven by the voluntary sector itself, and is entirely independent of government, we hope that the Department of Health will be supportive of the proposal as it develops, particularly as the proposal will be based on what organisations working with or representing patients, carers, service users and citizens recognise is needed at a national level.
6. **How should LINks be designed, including:**

- Remit and level of independence.
- Membership and appointments.
- Funding and support.
- Areas of focus.
- Statutory powers.
- Relations with local health Trusts.
- National coordination.

6.1 Some of our members are concerned about the prospect of local variability in the new system. Where there are few community development organisations in a locality, there is only a limited prospect for a meaningful LINks to emerge. While it is vital for LINks to retain their independence, it is also vital for the voluntary sector locally to be properly funded and supported in order to support the development of LINks. The Government will also need to address the potential conflict of interest brought about by the likelihood that some voluntary sector organisations that are providing services under contract to the NHS or local councils would also be eligible for membership of LINks.

6.2 In terms of national coordination, it is essential for individual LINks to have a mechanism by which issues can be coordinated regionally and, if necessary, escalated to a national level. It is also important for there to be a mechanism that allows the priorities and concerns of local LINks to be examined nationally to provide policy and decision makers at a national level with the insight of local service delivery from a patient, service user and citizen perspective. There will also be a need to consider what sort of national standards for LINks will be necessary to maintain an adequate quality of participation in all areas.

6.3 As mentioned above, the Patients Forum has also been working with other stakeholders to explore what sort of “national voice” is needed to more effectively reflect the patient perspective in to national policy making. This is an issue that we feel is in need of much greater exploration, and we would encourage the Committee to explore this issue in greater detail.

7. **How should LINks relate to and avoid overlap with:**

- Local Authority structures including Overview and Scrutiny Committees.
- Foundation Trust boards and Members Councils.
- Inspectorates including the Healthcare Commission.
- Formal and informal complaints procedures.

7.1 Some of our members have expressed a view that the Government’s map of patient and public involvement mechanisms is becoming increasingly complex and difficult to understand. It is obviously important that LINks are able to work effectively with the other components of the Government’s patient and public involvement system. However, it is important for the Government to be clear about the roles and responsibilities of each component, and particularly the expectations that they will have of local citizens in those processes. Thought will also need to be given how specialist commissioning arrangements can be opened up to patient and public involvement and made more transparent.

8. **In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?**

8.1 Consultation needs to take place at the earliest opportunity, and before any decisions have been taken locally. It is still too often the case that communities are presented with a fait accompli, and the NHS simply uses inadequate consultation mechanisms to effectively rubber-stamp a decision that has effectively already been taken.

8.2 In undertaking wider public consultation, it is important to ensure that the formal mechanisms for participation (such as LINks, or Foundation Trust membership) are not seen as substitutes for real and effective engagement. Formal mechanisms provide an important conduit to the wider community, but are themselves not sufficient. In undertaking wider public consultation, these mechanisms should be harnessed to reach out to the wider community. Real engagement costs money and time, and the NHS must be prepared to invest in consultation to ensure that the widest possible range of stakeholders are reached.

*Unnati Rennie*

The Patients Forum

*January 2007*
Evidence submitted by Peterborough Primary Care PPI Forum and Peterborough and Stamford Hospitals PPI Forum (PPI 3)

Members of the Peterborough Primary Care Patient and Public Involvement Forum (PPIF) and the Peterborough and Stamford Hospitals PPIF are very concerned that the government is proposing to replace PPIFs with Local Involvement Networks (LINks). As you will know this policy change was promulgated in the Department of Health document “A stronger local voice”, and comes after the very short period of existence enjoyed by PPIFs. We have already responded to the DOH document.

We firmly believe that the proposals for LINks reduce the effectiveness of any Public and Patient involvement when compared with their predecessor organisations (PPIFs).

We list below the differences that we perceive between PPIFs and LINks.

A PPIF has statutory responsibilities which include:
— monitoring and reviewing the services provided by the trust;
— canvassing the views of patients, users and carers about these services; and
— preparing reports and recommendations to the trust about those services, based on the views of patients and the public.

A PPIF has statutory powers which include:
— the power to collect information relevant to its functions from particular NHS organisations and other authorities and to require such organisations to respond within 20 working days; and
— the power to enter an inspect premises owned or controlled by the PCT.

The proposed LINks appear from the consultation document to have no statutory powers or responsibilities. We firmly believe that without statutory powers or responsibilities the LINks will not be effective and could be considered as “toothless”.

Agenda
— Forums set their own agenda and devise their own work plans and priorities without political or commercial interference; and
— LINks will have an agenda which, as proposed, appears to be susceptible to the influence of politicised or special interest groups.

The independence of an agenda is essential if the organisation is not to be perceived as following directions imposed by powerful lobbyists or special interest groups to the detriment of representing the patient base impartially.

Funding
— PPIFs were funded independently of local authorities or the local NHS.
— LINks will rely on the local authority to pass on funding.

Where funding is controlled by a body which may be influenced by local politicians there is a danger that funding might be delayed or curtailed if the funded body raises politically embarrassing issues. If local funding is unavoidable then it must be clearly and irrevocably ‘ring fenced’.

Volunteers
— PPIFs have generally been able to attract members because they offer the potential to “make a difference”. The PPIFs’ roles and structure were clearly defined and attracted members who have gained knowledge and experience since joining.
— LINks will attempt to build a membership drawn from local organisations with specific interests. By their nature these organisations attract members who have a specialist interest in a specific aspect of health or social care. The ill-defined terms of reference and lack of ‘clout’ will make LINks less attractive to independent volunteers.

Many of our existing members have serious doubts whether they wish to be part of what could easily become a “talking shop”. They also do not wish to have patient and public involvement steered by special interest groups, which by their very nature and purpose were created to represent a specific cause.
Monitoring Quality of Service and Standards

— PPIFs had a major role in monitoring services and processes within the health and care organisations. This role was clearly a major responsibility of the PPIFs.

— LINks seem to be vague on this pivotal subject. The key powers of access and response to enquiries are absent from LINks and it is difficult to envisage how they can effectively monitor quality and standards without these powers.

Existing forum members see monitoring of quality standards as a key role. One of the major enablers for effective monitoring was the statutory framework in which PPIFs worked. The need to CRB check members who may perform inspections was given as a reason why this enabler is not present in LINks. It is possible to have patient and public representative bodies that embrace both CRB checked individuals and those who decline to be checked. There is no reason why inspections should not be limited to those who have been checked.

It is also likely that some voluntary groups will have CRB checked members. We, therefore, cannot accept the Government’s position that inspection can no longer be allowed.

The Voluntary Sector

— As already stated many voluntary sector groups represent specific single issue groups of people. That is why they were founded and that is their legitimate purpose. It is difficult to envisage that such representation can take a broad neutral view of health and social care issues in the way that PPIFs have sought to do.

— There is a presumption within the document “a stronger local voice” that all the voluntary sector groups are constituted on the same basis. This is not true. Whilst large well organised groups eg Age Concern have full time staff who may be able to devote some time to a LINk many groups are run on a self help basis by sufferers and their family member carer. These people work extremely hard at their group and in providing care to their partners. They also do much unheralded pastoral work. We question whether such groups could provide effective membership of a LINk.

— This forum has invested a massive amount of its time to seeking to make links with the voluntary sector in this City. This has been met with minimal success.

— We believe that our greatest success in working with the voluntary sector was in co-opting advice and information from a voluntary sector group when we undertook a piece of work relevant to that body’s area of interest.

— We suggest that that level of link up is the right way forward and that widening the representation on PPIFs as currently constituted will provide the best way forward.

Section 11

— This forum welcomes the strengthening of section 11 regarding consultation as a progressive and beneficial reform.

Single Area Body

— The proposal to establish a single body to oversee one area based upon a social services area as proposed is a constructive move as for many health patients the treatment pathway spans both PCT and Acute trust services.

We believe that the PPIF organisation was just getting into its stride and possibly is now a victim of its own success, hence the intention to replace it with a ‘watered down’ version. If we are to avoid this, pressure must be brought to bear before the proposals are put before parliament.

Peter Edwards
Chairperson,
Peterborough Primary Care PPIF

Annette Beeton
Chairperson
Peterborough and Stamford Hospitals PPIF

11 December 2006
Evidence submitted by The Picker Institute (PPI 97)

SUMMARY

1. Picker Institute Europe welcomes the Select Committee’s Inquiry. Based on its evidence of patients’ experience in their NHS treatment and care, the Picker Institute urges the Committee:

— to support and promote the continuation of the national patient survey programme under the future regulator;

— to examine the best means to require trusts to demonstrate that they are involving patients in using survey results for quality improvement;

— to consider whether the Local Government and Public Involvement in Health Bill should be amended to enable the Secretary of State, through regulation, to impose such a duty on trusts; and

— to recommend to the Secretary of State the amendment of Section 155 of the Local Government and Public Involvement in Health Bill so as to include a power for the Secretary of State to impose duties:
  — to publish and share promptly with relevant LINks the information from patient surveys,
  — to assist LINks to analyse and understand that data, and
  — to involve LINks in the design and commissioning of future patient surveys.

— formally to welcome the new approach to patient/professional partnerships encoded in “Good Medical Practice”;

— to examine ways in which this partnership approach can be pursued, especially via education, training and continuing professional development, to ensure doctors uphold the Good Medical Practice standards;

— to recommend to the government that similar processes of revision should be forcefully pursued through the other health professions;

— to recommend to those professions that they adopt approaches to patient/professional partnership reflecting the new Good Medical Practice;

— to highlight to government and to the relevant health professions the priority need to develop up-to-date and effective models for patient feedback questionnaires relating to professional performance; and

— to recommend to the government and relevant health professionals that these feedback mechanisms be built into the current and forthcoming revisions to professional appraisal and revalidation systems.

2. About the Picker Institute

2.1 The Picker Institute is an independent health charity which works with patients, professionals and policy makers to promote understanding of the patient’s perspective at all levels of healthcare policy and practice.

2.2 It undertakes a unique combination of research, development and policy activities which together work to make patients’ views count. These include:

— Researching and evaluating patients’ experiences.

— Leading initiatives that make improvements happen.

— Building evidence to inform health policy.

2.3 The Picker Institute led the development of patient experience surveys in the UK. These go beyond simple measures of “satisfaction”, by enabling patients to report on their actual experience of various aspects of their care and treatment. The questionnaires are developed through holding focus groups with relevant patients to discover what aspects of care they focus on the most, followed by large scale surveys of patients, producing results which enable health professionals and managers to identify areas for improvement.

2.4 There is now a Department of Health requirement for every NHS trust to carry out an annual survey of patients. The Picker Institute is an approved provider of surveys for this programme, and acts as the national co-ordination centre for all the surveys carried out by acute trusts. The Picker Institute also provides bespoke survey services to NHS bodies and other organisations, including staff surveys as well as patient surveys. On the basis of this evidence and its other, independent research, the Picker Institute works to improve the quality of patient care with a variety of organisations involved in the NHS, in professional regulation and in representing patients’ views. It is consulted frequently by government and the Department of Health, as well as relevant All Party Groups in parliament.
2.5 The Picker Institute is not an organisation run for or by patients, but an independent charity with unrivalled research and practical knowledge of what patients say they experience in the NHS. This memorandum makes use of this evidence base to address the issue of “patient involvement”, arguing that this should be seen as, in many respects, distinct from the question of “public involvement”. The Picker Institute does work closely with organisations run for and by patients, and is an associate member of the Patients Forum, and would additionally support many of these organisations’ inputs to this Inquiry.

ANSWERS TO THE INQUIRY QUESTIONS

3. What is the purpose of patient and public involvement?

Distinguishing “patient” from “public” involvement

3.1 Like the Long-term Medical Conditions Alliance (LMCA), the Picker Institute believes the primary purpose of patient and public involvement should be to achieve a truly patient-led NHS.

3.2 However, although government and NHS policies and plans lump “patient and public involvement” together, the Picker Institute’s experience is that they need to be distinguished from each other, rather than conflated. One result of their conflation is that, while there have been a number of initiatives to establish public involvement, the latest of which is the Local Involvement Networks, there has been little attention to tackling what patients say they want.

3.3 Patients—that is, people who are or have recently experienced NHS care—and “the public” express different viewpoints about the NHS. The Populus study, which tracked the perceptions of 2,000 respondents representative of the population as a whole during 2005, was typical of all research studies in finding that:

“patients are generally more positive about the NHS than the population as a whole, exhibiting larger majorities in favour of the propositions that the NHS is improving, that it provides a good service overall and that it is at least as good as health services abroad”.

3.4 In part this is because the general population is more influenced in its perceptions by the media, hearsay and political opinions, whereas patients respond on the basis of their actual experiences of care. But there is a more important general truth: patients care more about the quality of their own treatment, and therefore their interactions with the service and with health professionals, than about how the service is organised, while citizens are more likely to address collective or societal issues of the organisation of health care, such as the pattern and nature of health care provision.

3.5 While we are all both citizens and patients (or potential patients) it is important to try to disaggregate the “public” and “patient” approaches to involvement. In a recent attempt to start this debate, the Picker Institute suggested some distinctions between what patients and citizens want from the NHS:

<table>
<thead>
<tr>
<th>Patients</th>
<th>Citizens</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fast access to reliable health advice</td>
<td>Affordable treatment and care, free at point of use</td>
</tr>
<tr>
<td>Effective treatment by trusted professionals</td>
<td>Safety and quality</td>
</tr>
<tr>
<td>Shared decisions and respect for preferences</td>
<td>Health protection, disease prevention</td>
</tr>
<tr>
<td>Clear information and support for self-care</td>
<td>Accessible local services plus centres of excellence</td>
</tr>
<tr>
<td>Attention to physical and environmental needs</td>
<td>Universal coverage and equity</td>
</tr>
<tr>
<td>Emotional support, empathy, respect</td>
<td>Responsiveness, flexibility, choice</td>
</tr>
<tr>
<td>Involvement of and support for family and carers</td>
<td>Participation in service development</td>
</tr>
<tr>
<td>Continuity of care, smooth transitions</td>
<td>Transparency, accountability and opportunity to influence decisions</td>
</tr>
</tbody>
</table>

3.6 While this table is intended to stimulate further debate rather than to be conclusive, the eight terms in the “patients” column here are definitive. These are the eight key areas of focus identified by patients’ reporting of their own experiences of care in all the national patient experience surveys carried out for the NHS since 1998.

3.7 Although the terms in the “citizens” column, and the exact nature of overlaps and distinguishing points may be open for discussion, the key point is that patients have defined what they want from NHS treatment and care, and it is qualitatively different to the collective aspirations that citizens or the general public might hold.

3.8 With regard to the “purposes” of involvement, therefore, there should be two sets of related, and at times overlapping, but necessarily distinct discussions. If one “purpose” of involvement should be to ensure that the NHS is accountable, for example, then this is likely to relate much more to public than to patient involvement. By contrast, if one “purpose” is to improve the effective delivery of care by health professionals, this is more likely to relate to patient involvement.

3.9 Looked at from another perspective, patient experience as reported by masses of patients themselves through the surveys, requires that we look at specific areas for service improvement, which may be different from the priorities for action generated by public opinion as a whole.

Purposes of Patient Involvement

3.10 The greatest potential benefits from involving patients, as distinct from the public, would lie in improving the effectiveness of care and treatment through transforming the interaction between patients and health professionals.

3.11 There is a growing body of evidence to demonstrate what such a focus could achieve. Engaging patients in treatment decisions and in managing their own health care has been shown\(^50\) to:

- improve the appropriateness of care;
- improve the health outcomes;
- reduce risk factors and prevent ill-health;
- lead to more cost-effective outcomes;
- moderate demand;
- improve safety; and
- reduce complaints and litigation.

3.12 This kind of patient involvement is fundamentally different to the involvement of the public in service design, resource allocation, or in accountability mechanisms. Engaging patients in treatment and self-care requires a change in culture from the paternalism which still characterises most transactions between patients and the NHS, to a “partnership” approach in which patients are supported to engage in shared decisions.

3.13 Key elements of the partnership approach include:

- the communications skills and training of doctors, nurses and other health professionals and allied staff;
- clear and comprehensible information which patients can trust, and which can be personalised to them;
- an environment in which not only patients but also their carers and families feel comfortable and welcomed; and
- an approach to patients’ care plans which takes full account of the fact that it is patients, outside of the short intervals in which they meet health professionals, who take responsibility for and manage their conditions, and which prepares and supports them to do that.

UK’s Record on Patient Involvement

3.14 There have been various attempts to promote public involvement in the NHS, most recently through initiatives like the CPPIH and PPI Forums, and now LINks. By contrast there has been very little progress on promoting patient involvement. Success has been patchy and dependent on the enthusiasm of individuals rather than a national steer. Evidence from the patient experience surveys suggests that, while patients have experienced significant progress in the way some aspects of health care are managed and delivered, there has been little or no improvement in many of the eight key areas of focus outlined in 3.5 above. Moreover, international comparisons suggest that the UK has a significantly poorer record on patient involvement than other advanced industrialised countries.

3.15 In 2005 the Picker Institute reviewed evidence from the 19 national patient surveys that had been completed since 1998, involving more than one million patients.\(^51\) Clear improvements over time had been experienced with regard to several of the areas targeted for action by the government and the NHS—including waiting times for GP and outpatient appointments, and faster access to cancer specialists, for example. Patients continued to express high levels of trust and confidence in health professionals.

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\(^50\) The evidence for all of these effects is reviewed in “Patient-focused interventions: a review of the evidence”, Angela Coulter and Jo Ellins, the Picker Institute for the Health Foundation, August 2006, ISBN 0 9548968 1 5, available via the Picker Institute website.

3.16 However, in areas of focus for patients themselves, there had been little improvement over those seven years. For example, in the key area of involvement in decisions and respect for patients’ preferences:

- in 2005, 69% of primary care patients said they were definitely involved as much as they wanted to be in decisions about their care—fewer than in 2003 when the figure was 73%. Only 59% were involved as much as they wanted to be in medication decisions;
- in 2004, 21% of outpatients and 26% of A&E patients said staff didn’t always listen carefully to what they were saying—no improvement on previous years;
- in 2004, only 53% of inpatients said they definitely had a say in decisions about their treatment. For outpatients the figure was 70%; for A&E patients 64%; for coronary heart disease patients 64%; and
- the proportion of cancer patients expressing satisfaction with their involvement in decisions fell from 89% to 84% between 2000 and 2004.

3.17 As another example, in the key area of “clear, comprehensible information and support for self-care”, there had been significant improvements in the provision of information to patients with cancer and coronary heart disease (both priority areas within the NHS plan), but there were still severe shortcomings more generally:

- in 2005, only 61% of primary care patients said they received enough information about the possible side-effects of their medicines, the same proportion as in 2003;
- in 2005, 43% of stroke patients said they were not given information about dietary changes that might prevent another stroke, and 33% said they were not given information about physical exercise;
- in 2004, 40% of inpatients, 37% of outpatients and 61% of A&E patients said they were not told about danger signals to watch out for—the same proportions as in previous years’ surveys. Repeat surveys in 2005 again showed little change.

3.18 To assess whether the UK is any better or worse in involving patients in their own care than other countries, the Picker Institute analysed data from six countries in 2004 and 2005—Australia, Canada, New Zealand, Germany, the USA and the UK.52 While none of these excelled in promoting patient-centred care, UK patients were receiving less support for engagement in their healthcare than in any of the other countries. Fewer UK patients were involved in treatment decisions; they were less likely to have been invited to review their medication or to have been given information about possible side-effects; they received less help with recovery and rehabilitation; and they were the least likely to report that their doctor had given them advice on preventing ill-health.

4. What form of patient and public involvement is desirable, practical and offers good value for money?

Evidence

4.1 The future of patient involvement depends critically on the continued compilation of an evidence base that can be used to analyse patients’ experiences en masse, to identify areas for improvement, and to measure progress. The key to this is the national patient survey programme. This programme requires each NHS trust organisation to conduct an annual survey of patients’ experiences. There are several main benefits.

4.2 The first benefit is that the results contribute to a national picture of the quality and effectiveness of health care. They go beyond simple measures of “satisfaction” by breaking down the care experience into its various elements in order to identify the strengths and weaknesses of NHS care nationally—and therefore the potential targets for improvement—through patients’ own reported experiences.

4.3 The second main benefit is that they inform each trust of its own strengths and weaknesses in patients’ eyes. Moreover, the results each trust receives can be “benchmarked” against the national picture, showing how well the trust performs in each area vis à vis its peers. The straightforward statistic that, for example, 30% of this trust’s inpatients were given inadequate information to manage their own care upon discharge, will be given context by knowing that this placed it among the worst 20% of trusts.

4.4 A third benefit of the existence of this system is that it makes available a set of resources and a “market” of providers upon which NHS bodies can draw to conduct additional surveys of their users or client populations outside the national programme itself. For example, commissioners may ask a survey provider to help them identify the priorities of a particular patient group in their locality.

4.5 A fourth potential benefit of the evidence base is to feed into structures of public involvement. The Picker Institute suggests (see below) that the LINks should make regular use of the survey information to hold their local NHS providers and commissioners to account.

52 “Engaging patients in their health care: how is the UK doing relative to other countries?”, Angela Coulter, Picker Institute Europe, 2006.
4.6 For these benefits, the programme is relatively cost-effective. It merely requires each Trust to spend a few thousand pounds annually on “customer care” surveys which, as a ratio to their expenditure budgets as a whole, is probably minimal compared to customer care expenditure in other parts of the public sector, and certainly to private sector market research.

4.7 The national patient survey programme is, however, not secure. In its short lifetime of less than a decade it has already had three masters and is due to have a fourth, when the Healthcare Commission is amalgamated with the National Social Care Inspectorate and the Mental Health Commission.

4.8 The Picker Institute therefore urges the Select Committee:

— to support and promote the continuation of the national patient experience survey programme under the future regulator.

Using the Evidence Base (I)

4.9 Currently, however, the patient survey is open to the criticism that in itself it does not create change. There is a requirement for trusts to carry out the surveys, but no requirement to put the results to work for quality improvement.

4.10 The Picker Institute, in its role as a survey provider, offers a package to trusts which includes a bespoke service to help the trust use the results to involve patients in developing an Action Plan for quality improvement. This remains voluntary and is an additional expense for the Trust.

4.11 There are some mechanisms in place that are supposed to take advantage of the evidence base. PPI Forums, for instance, are required to monitor the action plans that are supposed to result from Trusts’ patient surveys. The extent to which this has been done—and the extent to which trusts respect and enable this role—are uncertain.

4.12 There are also departmental standards, on which clinical governance committees are expected to take a lead. These Standards for Better Health (Department for Health 2006) include “core” (compulsory) and “developmental” standards, which are in effect good practice guidelines but do not place duties on the committee or the trust.

4.13 The “core” standard that relates to patient involvement states that:

C17 The views of patients, their carers and others are sought and taken into account in designing, planning, delivering and improving health care services.

4.14 The other key standards relating to patient involvement fall into the “developmental” category and are as follows:

D8: Health care organisations continuously improve the patient experience, based on the feedback of patients, carers and relatives.

D9: Patients, service users and, where appropriate, carers receive timely and suitable information, when they need and want it, on treatment, care, services, prevention and health promotion and are:

(a) encouraged to express their preferences
(b) supported to make choices and shared decisions about their own health care.

D10: Patients and service users, particularly those with long-term conditions, are helped to contribute to planning of their care and are provided with opportunities and resources to develop competence in self-care.

4.15 The “developmental standards” are those to which trusts should be “progressing”. The Healthcare Commission states that it will begin assessing such progress within its “annual health check” programme; but in 2006–07 this will not include standards 8–10.

4.16 If a “patient-led NHS” is really the priority which the government says it is, then we must move more quickly beyond this situation, to create more leverage for the active use of the evidence from patient feedback. Some combination of additional regulatory requirements, clinical governance duties, performance management and inspection measures, and/or other incentives may be needed.

4.17 The Picker Institute therefore urges the Select Committee:

— to examine the potential roles of regulation, inspection and other interventions to require trusts to demonstrate that they are involving patients in using their survey results to set priorities for quality improvement; and
— to consider whether the Local Government and Public Involvement in Health Bill should be amended to enable the Secretary of State to impose such a duty on trusts.

53 http://www.healthcarecommission.org.uk/serviceproviderinformation/annualhealthcheck/howitworks/developmentalstandards.cfm
Using the Evidence Base (2)

4.18 The Picker Institute suggests above that the purpose of patient involvement should be improving the effectiveness of care and treatment through transforming the interaction between patients and health professionals.

4.19 The second use to which the evidence base should be put, therefore, is to challenge and confront outdated medical professionalism and organisation. In the NHS Plan in 2000, the government seemed to recognise the core of the problem:

"The relationship between patient and service is too hierarchical and paternalistic. It reflects the values of 1940s public services."

4.20 There have been some important initiatives since then, such as more emphasis on patient choice, but this kind of reform is often resisted by health professionals. There is little evidence that these outdated attitudes have changed, and they remain an obstacle preventing patients from playing the active role that most say they want to play. Moving forward must involve engaging clinicians as well as patients, challenging them, and encouraging them, to see patients as their partners in the process of treatment and care, not simply as passive victims of ill health. The government and the health service senior management will need to be bolder in challenging the medical professions to modernise their training, education and performance measurement.

4.21 Clinicians will need a new set of skills and competencies that barely feature in current training. These will include how to develop the health literacy of their patients; how to enable shared decision making; and how to support patients’ self-care. All of these require excellent communication skills.

4.22 From their side of the partnership clinicians will need to:

— guide patients to appropriate and personalised sources of information on health and health care;
— educate patients on how to protect their health and to prevent the occurrence or recurrence of disease;
— elicit, listen to and understand patients’ preferences;
— communicate clear information on risk and probability;
— share treatment decisions and respect patients’ part in those decisions; and
— provide support for self-care and self-management.

4.23 Some new building blocks are being put in place within the NHS to support this culture change. For example, work is proceeding on the idea of providing an “information prescription” to patients; and on a “kitemark” accreditation scheme for information providers. But the culture change itself has to come through the professions. This will require a concerted campaign to persuade the health professions of the need for culture change, based on the mass of feedback evidence that is now available from patients.

“Good Medical Practice”: Progress, but more Needed

4.24 A positive recent development is the revision of the General Medical Council’s “Good Medical Practice”, effective from 13 November 2006. This now states that among “the duties of a doctor registered with the GMC” is to “Work in partnership with patients”, which means:

— listen to patients and respond to their concerns and preferences;
— give patients the information they want or need in a way they can understand;
— respect patients’ right to reach decisions with you about their treatment; and
— support patients in caring for themselves to improve and maintain their health.

4.25 But “Good Medical Practice” is, again, a set of guidelines. These will only be effective in creating change if there is continued momentum, from the GMC, through the Postgraduate Medical Education and Training Board, the Royal Colleges and deaneries, and from management throughout the NHS, to provide doctors with the training, the formal requirements, and the incentives that will encourage them to uphold these standards. The Picker Institute is working with the GMC and others to help create such momentum, based on a research programme which has been looking at effective ways to measure performance and for patients to give feedback on their clinicians.

4.26 The Picker Institute urges the Select Committee:

— formally to welcome the new approach to patient/professional partnerships encoded in “Good Medical Practice”; and
— to examine ways in which the momentum for this partnership approach can be pursued, especially through training and through continuing professional development, to ensure doctors uphold the Good Medical Practice standards.
4.27 At the same time it must be recognised that the GMC covers only one part of the health workforce. The Picker Institute therefore urges the Select Committee:

— to recommend to the government that similar processes of revision should be forcefully pursued through the other health professions; and

— likewise to recommend to those professions that they adopt approaches to patient/professional partnership that reflect the Good Medical Practice revision.

Additional Needs for Evidence

4.29 While the value of the national patient survey is emphasized throughout this memorandum, it cannot meet all needs for patient feedback. In particular, the surveys are carried out at an organisational level (by trusts) and therefore do not produce results at the level of the clinical team or the individual clinician. There is a need to discover what mechanisms can work at these levels and to integrate them into performance measurement.

4.30 The Picker Institute is currently running the “Patient Centred Professionalism” project which aims to:

— learn more about what patients and the public expect of doctors, their professional standards and how these are regulated, and where the obstacles to culture change might lie;

— disseminate these research results to inform and influence principles and, most importantly, attitudes and practice; and

— share experiences and ideas of good practice widely amongst an international network of partners.

4.31 One aspect of the research has been to review all the available models, from several countries, of questionnaires that enable patients to comment upon clinicians’ performance. This review identified the best models, but still found them wanting with regard to some aspects of care that are important to patients. It therefore recommended that:

— questionnaires more attuned to the patient-engagement agendas of today are developed and include a fuller range of questions; and

— further consideration is given to the development of questionnaires targeted to specific types of condition or specialty as well as those designed to be administered across a broad range of settings.

4.32 The Picker Institute would therefore request the Select Committee:

— to recommend to the government and to the relevant health professions that there is a priority need to conduct further research to develop up to date and effective models for patient feedback questionnaires relating to professional performance; and

— to recommend to the government and relevant health professionals that these feedback mechanisms be built into the current and forthcoming revisions to professional appraisal and revalidation systems.

5. How should LINks be designed?

Use of the Evidence Base (3)

5.1 The change in professional culture described above will be greatly facilitated if other parties within the health system are pushing for the patient/professional partnership approach.

5.2 It is here that the LINks can potentially help to exert pressure for improvement. It should be a central part of their role to receive and understand relevant data from the patient surveys, and to act as advocates for the creation of action plans for change—including organisational change to the way services are delivered, cultural change to the practice of the health professionals involved, and action planning for quality improvement.

5.3 The Picker Institute welcomes the new proposals for LINks. We agree with the LMCA that it is desirable for these to cover both social care and health, to relate to geographical areas rather than specific institutions, and to work closely with the commissioners of health care.

5.4 The Picker Institute is concerned that LINks may struggle to clarify and establish their roles. This is a particular danger with regard to the gathering, analysis and use of information and intelligence on what patients and the public want. Making effective use of such resources is challenging for small organizations, and especially for lay people. But the problems will be greatly exacerbated if government guidance and regulation does not clearly point the way.

54 “What do you think of your doctor?”, Alison Chisholm and Janet Askham, Picker Institute Europe, 2006.
5.5 The government’s most recent explanation of what LINks should and can be doing places considerable emphasis on the gathering of intelligence and feedback from patients. For example:

“LINks will therefore be engaged in monitoring by actively seeking views directly through contributions from individuals and groups, and indirectly from representatives or advocates, from complaints and PALS, through surveys, through comment cards, through websites, and through other methods. Their strength will be that they are able to engage with a large number of people rather than relying on the experiences of a few centrally appointed members.”

5.6 Surprisingly, the national patient survey programme is not mentioned once in this document. There is no reference to the existing evidence base. There is no suggestion that there should be a responsibility for trusts to publish and share this information with relevant LINks in their user area; let alone a requirement for commissioners and providers to involve LINks in the planning and design of future surveys.

5.7 As a result there is a real and present danger that LINks will waste time, energy and resources duplicating the evidence, reinventing the wheel of survey techniques, or worst of all, struggling with poorer quality evidence when a high quality, properly validated evidence base already exists and continues to develop.

5.8 This can be remedied. Section 155 of the Local Government and Public Involvement in Health Bill enables the Secretary of State by regulations to impose duties on a service provider to respond to information requests from LINks. With slight amendment this Section, and the subsequent regulations, could remedy the omissions.

5.9 The Picker Institute therefore urges the Select Committee:

— to recommend to the Secretary of State the amendment of Section 155 of the Local Government and Public Involvement in Health Bill so as to include a power for the Secretary of State to impose duties:
  — to publish and share promptly with relevant LINks information from patient surveys;
  — to assist LINks to analyse and understand the data; and
  — to involve LINks in the design and commissioning of future patient surveys.

5.10 The Picker Institute agrees with the LMCA and the Patients Forum that there should be an appropriate and effective national presence for patient and public involvement, driven by the voluntary sector, into which the LINks could feed.

Don Redding
Head of Communications
Picker Institute
10 January 2007

Evidence submitted by Redcar and Cleveland PPI Forum (PPI 4)

1. The Redcar and Cleveland Patient and Public Involvement Forum met on Monday 8 January to discuss the questions posed by the Health Committee New Inquiry—Public and Patient Involvement in the NHS Terms of Reference. Their response is as follows:

2. The purpose of patient and public involvement is to monitor key aspects of NHS provision, opening all aspects of services to the patient and publics. Public and Patient Involvement should also act as a critical friend to the NHS.

3. Effective monitoring and meaningful patient and public involvement of selected health matters offer the most desirable, practical and best value for money.

4. The existing systems for patient and public involvement is being reformed in order to ensure a wider cross section of patient and publics views are listened to on their journey throughout the NHS system.

5. LINks should be independent from the NHS with wider involvement of other networks. When appointing members to the LINks, there should be total involvement of the current members. The funding should be ring fenced and LINks should focus on all aspects of health and social care within Local Authority boundaries. LINks should have the same statutory powers as PPI Forum powers currently hold, ie the right to inspect and the right to a response. The relations with local health Trusts should remain as they are for PPI Forums—indepedent from but working with the NHS—but involving all Trusts in the Local Authority area rather than just dealing with one Trust as in the current PPI Forum system. National co-ordination is essential to share information and have any national issues addressed.

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56 Ibid, paragraph 1.43.
6. LINks should remain independent from Local Authorities and OSC, and Foundation Trust Board and Members Council, however work with these bodies, especially on specific issues. LINks should work with inspectorates, including the Healthcare Commission, similar to how PPI Forums currently work with such bodies, i.e., take part in the Annual Health Check and receive Quality Outcome Framework reports etc. LINks involvement in formal and informal complaints should be minimal, signposting complaints to the relevant authorities.

7. Wider public consultation should be carried out under the circumstances as currently described under Section 11 of the Health and Social Care Act 2001, however to be mindful of possible changes of legislation.

Redcar and Cleveland PPI Forum
8 January 2007

Evidence submitted by Richmond and Twickenham PCT PPI Forum (PPI 140)

The Richmond and Twickenham PCT PPIF is a small but increasingly active forum. There are no acute hospitals within the PCT and local authority boundaries; residents therefore need to travel outside the borough for delivery of acute medical and surgical care services.

Forum members have questioned why systems for patient and public involvement are being reformed after only three years; informed by experience, forum members recognise that it takes time for people drawn from a variety of backgrounds and experience to learn to work together and choose and take forward a work programme, particularly when seeking information and making judgements in relation to such a complex area as the delivery of health care. However, Forum members now look forward positively to being involved in the establishment of a local LINk and are committed to progressing the agenda for public and user involvement in the planning, commissioning and provision of local care services.

Our submission of evidence to the Health Committee, takes account of the recommendations set out in the Department of Health’s document: A stronger local voice, July 2006 and the Government response published in December 2006. We also note the first reading on 13 December 2006 of the Local Government and Public Involvement in Health Bill and the contents of Part 11, Patient and Public Involvement in Health and Social Care. We trust that the findings and recommendations of the Health Committee Inquiry into Public and Patient Involvement in the NHS will be taken due account of as the Local Government and Public Involvement in Health Bill progresses through Parliament, particularly in advance of the Report stage.

We respond to the following points, which relate to the terms of reference for the Inquiry:

1. How Should LINks be Designed:

1.1 Remit and level of independence

We support the recommendation that LINks:
- should be coterminous with each local authority with social service responsibilities;
- should be independent and have the powers to develop their own priorities and agenda;
- will have statutory powers enabling them to require NHS and social care bodies to provide information about their services and priorities and to respond to recommendations; and
- will provide a flexible way for local people and communities to engage with health and social care organisations and ensure that service providers are made more accountable to the public.

We strongly support the plan for LINks to have responsibility for monitoring both health and social care provision over the whole patient journey.

The importance of being able to work closely with the Health Overview and Scrutiny committee is recognised but at the same time, independence must be ensured.

Key points:
- LINk Independence.
- A structure allowing monitoring of the whole patient journey.

1.2 Membership and appointments

The arrangements for organising the recruitment and signing up of members to the LINks should be handled at local level, by the host organisation. There are existing models readily available within the charitable and voluntary sector for recruiting to organisations whose members are both organisations and individuals.
There will need to be a “management board” or similar structure for the LINks and although this board will be accepting nominations from member organisations and individuals in due course, it will be advantageous if individual members of the existing local PPIFs, if willing, are automatically selected as members of the management board in the first year. They have already been through a valid recruitment process, including CRB checks and have demonstrated their sustained commitment to the public and user involvement agenda.

We recognise that it is intended there will be flexibility for LINks to organise their own structures but when LINks begin operation it will be vital that there are members with experience in place, to move the process forward and facilitate LINk independence and development. PPI forums took considerable time to develop cohesion and direction; many signed up members were lost at an early stage due to disillusionment with the forums’ capabilities to function effectively and it would be very regrettable if the experience gained through PPI forum membership was not to be fully utilised within the new LINks. It is important that host organisations do not lead but support, hence the importance of the LINks being able to operate as independent organisations right from the start.

Key points:
— Recruitment for LINks to be handled at local level.
— PPIF members to be amongst the founding members of the new LINks in order to benefit from their public and user involvement experience and commitment.

1.3 Funding and support

LINks are to be required to take on a significant and extensive role. In order to be effective each LINk will need significant administrative and training support, with more intensive support on start-up. If LINks are not sufficiently resourced they will be overwhelmed and fail. In the early days of the introduction of forums, members felt generally unsupported, particularly in relation to the provision of practical support at local level and funding support for front-line activity. This was a major disincentive to early member commitment.

The funding to be provided to local authorities to develop LINks should be clearly defined and monitored.

It is not enough to say there are representative voluntary and community organisations (VCS) already in place that will be able to provide information and user experience to feed into the LINks, these organisations are hard-pressed already. VCS organisations frequently find it difficult to engage with and respond to public consultations, participate in project working groups or attend special interest meetings etc as much as they would wish. It is not that they do not want to engage fully, they just don’t have sufficient spare capacity.

The host organisation must be based within the locality covered by the LINk. A very significant weakness of the PPIF structure has been that forums are not supported by an organisation based within their locality. It is essential that the host organisation is easily accessible and has wide knowledge and experience of the local voluntary and community sector (VCS). This will facilitate the development of the LINK as an integral part of the VCS sector, with rapid development of appropriate membership and involvement. Whilst recognising the constraints on funding, some members feel very strongly that the LINks will require high profile, accessible “shop-front” premises in order to engage with and attract local interest and involvement.

Key points:
— The funding for LINks provided through local authorities should be clearly defined and monitored.
— The host organisation must have a knowledge of the local health and social care sector and be based in the local community.
— It is essential that LINks are provided with dedicated accommodation and administrative support, appropriate and sufficient to enable the objectives and remit of LINks to be achieved.

1.4 Areas of focus

As the LINks are to be set up as independent organisations with the ability to set their own agendas within the scope of LINks’ statutory functions, it is likely that the “areas of focus” will vary widely between LINks organisations and will be influenced by local priorities and the strength of the involvement of various groups and individuals. This freedom to set their own agendas is vital and from experience gained within the voluntary and community sector (VCS), it is clear that the enthusiasm and commitment of VCS members is enhanced if there is freedom of choice of focus, recognising the key role that it is proposed that LINks will have in contributing to the commissioning and planning of services, in addition to provision.
Key point:
— The freedom for LINks to set their own agendas is essential, dependent on local priorities and interests.

1.5 Statutory powers

We note that the current legislation on health service consultation Section 11 of the Health and Social Care Act is to be simplified and strengthened in the new legislation. It has been recorded in the press and elsewhere that on a number of occasions consultation processes have not been initiated appropriately by healthcare organisations. The provision of health and social care is currently moving through a period of very significant change and it is essential that the message is clear that consultation processes are not a matter of choice for health and social care organisations but a clear statutory requirement. [We note the Local Government and Public Involvement in Health Bill, Part 11 Clause 163, Duty to consult users of Health services.].

More recently in the government’s response to A stronger local voice (1.41) the government has responded to PPIF’s concerns that the power to enter health care premises was not to be provided for LINks. We note the statement: “We therefore plan to provide LINks with the power to enter health and social care premises (with some exceptions) and to observe and assess the nature and quality of services.”.

Patient and Public Involvement Forums have been extremely concerned that this power was not to be continued within LINks. It has probably been the most effective power that the PPI forums have been able to use when observing and assessing the nature and quality of specific services. It is vital that LINks are provided with this power. [We note Local Government and Public Involvement in Health Bill, Part 11, Clause 156 Service-providers duties to allow entry by local involvement networks.].

Key points:
— We support the strengthening of the consultation process.
— We applaud the decision to provide LINks with the power to enter health and social care premises to observe and assess services.

1.6 Relations with local health trusts

Within the current patient and public involvement system the PPIF’s engagement with their local healthcare trusts is variable. With many trusts the relationship is constructive and becoming more so over time. An increased emphasis on user and public involvement within the criteria used for measuring and benchmarking a trust’s annual performance will advance this process, facilitated by the healthcare organisations being required to address specific standards in relation to engagement.

It is obvious from PPIFs’ experience that user and public involvement needs time to become established within each local community. Individuals are often actively involved in a voluntary or community organisation that serves their own or their family’s particular interests and needs. The individual knowledge that they gain is extremely valuable, as it is based on practical experience, but to draw all these experiences together to contribute to the wider debate and decision-making process concerning the delivery of local services is complex. It will require the commitment of health and social care providers and commissioners as well as the LINks and other public and user representative bodies.

Key point:
— The success of the public and user involvement agenda will require the commitment of health and social care providers in addition to that of LINks and other public and user representative bodies.

1.7 National coordination

Whilst recognising that a representative national organisation with regional representation will be necessary to form the hub and spokes of a national network, we believe that the focus should be on the activity of LINks at the local level. LINks should be encouraged to communicate freely with each other, benefiting from practical networking and the sharing of experience. We recommend that the engagement at national level should follow the model proposed for LINks, ie that the network model should provide for inclusiveness and not develop into an exclusive membership of a limited number of LINks or individuals, who then become the “voice” of all LINks. Membership of the national representative group should be through election and with limited terms of office to allow for a changing cohort of members drawn from as wide a spectrum as possible.
During the period of development of PPIFs up to and including the present, the issue of which PPIF members are presumed to represent the wider membership has been a matter of continuing concern. The process for nomination and election of representative members should be effectively supported and acknowledge that potential nominees will require appropriate information on the role and responsibilities, encouragement to participate and support through training.

Key point:
— A LINks representative body at national level will be required but the focus of attention should be on the activity of LINks at local level.

2. How Should LINks Relate to Avoid Overlap With:

2.1 Local Authority structures including Overview and Scrutiny Committees

We believe that LINks must ensure their independence. However, working constructively with health overview and scrutiny committees (OSCs) will be essential in order to maximise capacity and ensure that HOSCs are informed by as wide a range of users and the public as possible; the two structures should be complementary to each other. Our PPIF has developed a constructive relationship with the local authority’s HOSC. Two PPIF members are currently co-opted as members of the HOSC, one as official representative of the PPIF and the other co-opted for their broad experience relating to health and social care. However, we are aware that there are still PPIFs that have minimal contact or dialogue with their local HOSC.

Key point:
— Working constructively with health overview and scrutiny committees will be essential in order to maximise capacity and ensure effective exchange of information.

2.2 Foundation Trust boards and Members Councils

As the role of LINks is to be structured around the care pathway it will be essential that LINks connect with local foundation trusts, as with any other healthcare organisation. It is expected that members of the foundation trust, who represent the local community interest, will be encouraged to become LINK members. It will be up to the local LINk to decide how to connect most effectively with health and social care providers and to recognise the diversity of organisational structures. This understanding of the complex health and social care environment will need to be developed with the support of appropriate training.

Key point:
— As the role of LINks is to be structured around care pathways, LINks will need to connect with Foundation trusts as with any other health or social care provider.

2.3 Inspectorates including the Healthcare Commission

It is to be expected that inspectorates will promote best practice in relation to user and public involvement by making full use of LINks by involving them in assessment processes. All bodies involved in monitoring the delivery of health and social care should maximise opportunities for engaging service users and the public and co-ordinating their inspection activities. It is recognised that with the development of regulation and inspection bodies over the past few years, there has been an excessive amount of duplication, which in itself causes disruption to the organisations being monitored, reviewed or inspected.

Key point:
— It is to be expected that inspectorates will promote best practice in relation to user and public involvement by making full use of LINks by involving them in assessment processes.

Formal and informal complaints procedures

Users often find the NHS complaints procedure convoluted, extended and not infrequently come out at the end of the process still dissatisfied. The system has been the subject of research and reform on a number of occasions over the years, the latest addition to the process being the NHS Redress Bill published in November 2006.

The successful introduction of the Patient Advice and Liaison Service (PALS) into NHS trusts providing informal access to users with concerns about healthcare is recognised and the PALS department within our PCT has been a very useful first-line contact for raising issues of concern to the PPIF. Due to their success
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the PALS departments of trusts are now becoming somewhat overstretched but it is envisaged that LINks will find it appropriate and productive to build an effective dialogue with local PALS departments. It is not considered appropriate that LINks should get involved with individual complaints, either the informal concerns voiced through PALS or the formal written complaints taken forward through the NHS complaints procedure. However, it will be appropriate and necessary as part of the LINk information and monitoring role that providers of health and social care services automatically provide LINks with copies of the routine complaints and adverse incident reports that are required to be produced routinely for reporting and learning purposes. These reports and other reports that LINks will receive from organisations and individuals will enable LINKs to monitor general trends and follow-up specific issues where it appears the issue may indicate a wider area of concern.

Key point:
— Links should receive copies of the routine reports on complaints and adverse incidents that are compiled as a reporting requirement by health and social care providers.

2.5 In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

The current legislation on health service consultation places a duty on all NHS organisations to make arrangements to involve and consult patients and the public in the development, planning and operation of services and particularly in the event of a significant change to an existing service. The current consultation requirements are probably sufficient in breadth but not effectively implemented and we strongly support the view that the legislation on consultation is to be strengthened. Trusts are not sufficiently aware of their responsibilities or, perhaps because of practical pressures attempt to avoid or minimise the process. Whilst it is recognised that consultation exercises divert the energy and time of the personnel involved and are therefore a resource issue for the organisations involved, it is essential that that the current legislation is strengthened and that very clear guidance is issued as to when public consultation exercises must be carried out.

PPIFs have sometimes lacked the capacity to be effectively involved in public consultation processes due to the low number of members of the average PPIF (there is a minimum requirement of seven members). However, the development of LINks with a much wider network will provide an opportunity for much more effective communication with, and involvement of users and the public in consultations. LINks will have the ability to connect with their member organisations and receive member views and responses to the consultation. During the consultation period, HOSCs will be able to enhance their response to the consultation process through information provided to them by the LINk. However, the capacity of LINks to engage with users will be dependent on the administrative resources made available to them via the support organisation.

Key point:
— It is essential that that the legislation is strengthened and that very clear guidance is issued as to when public consultation exercises must be carried out.

Margaret Dangoor
Vice Chair
Richmond and Twickenham PCT Patient and Public Involvement Forum

January 2007

Evidence submitted by the Royal Brompton PPI Forum (PPI 59)

The joint forum members for the Royal Brompton PPI Forum wish to make known that they consider the following points of paramount importance to the setting up of the LINks project:
— LINks must maintain independence and allow for participation at different levels.
— LINks to retain right of inspection.
— LINks to have the ability to listen to the local community for comments on services.
— LINks must ensure programme has close links with Trusts, social services.
— A national body is needed to oversee all LINks and share best practice. Also to provide a centre for local LINks to feedback information on topics that could be of national interest and to give greater credibility and unity. It was suggested that this could be the Healthcare Commission (HCC).
— Resources; need to be ring-fenced and need to include enough for two staff and an office and a discretionary budget for research and projects. It was suggested that budgets should be on a five year basis and should total around £200,000 per year per borough.
— Public profile.
— Every Local Health Authority to be required to have an Overview and Scrutiny Committee dedicated to Health and Social care and which includes professionals with the relevant knowledge to make a meaningful contribution.
— Members need to get involved in local services and committees allowing for there to be special focus groups for the Acute Trusts or Mental Health issues.
— Groups need sufficient time to disseminate information to members and feed back to Health Select Committee.
— Local interest groups that are getting involved in LINks should be required to declare any interests in Local Government contracts.
— Participation should be diverse and include a range of different communities.
— Proper arrangements should be made for incorporating forums into the work of Links and there should be some mechanism for work to continue within Links with specific NHS Trusts.

Royal Brompton PPI Forum

January 2007

Evidence submitted by the Royal College of Nursing (PPI 134)

SUMMARY

1.1 The Royal College of Nursing (RCN) believes that the achievement of effective and efficient systems of care depends upon the meaningful involvement and engagement of patients and the public in the planning, management and delivery of health services.

1.2 We also believe that the involvement and engagement of patients, carers and practitioners is an essential characteristic of the caring process which enables the development of partnerships and the empowerment of patients, practitioners and the public that we serve.

1.3 The RCN believes that the development of government policy in the representation of patients and the public must recognise and value these factors if it is to promote effective representation of patients and increase the involvement of the public in the provision of health services. However, the RCN is concerned that rather than strengthening the representation of the patient and public involvement in the planning, management and delivery of health services, the advent of Local Involvement Networks (LINks) will ultimately weaken the process that had previously been developed.

1.4 The RCN believes that in order to build and develop effective and meaningful patient and public involvement mechanisms, it is crucial to ensure that they have the power to influence the shape of the commissioning and provision of healthcare services in the local area.

INTRODUCTION

1.5 The RCN has a membership of over 390,000 registered nurses, midwives, nursing students and health care assistants. The organisation is the voice of nursing across the United Kingdom and the largest professional union of nursing staff in the world.

1.6 RCN members work in a variety of hospital and community settings and play an important role in developing new services. Involving patient organisations is important to the work that the RCN has been doing over recent years when considering the impact of policy on nurses and nursing practice. Central to this is the impact on service delivery and patient care.

What is the purpose of patient and public involvement?

2.1 Public and patient involvement is central to the Government’s drive to increase patient choice and to promote greater patient and public input to their services. That involvement is a resource that will inform the thinking and decision-making of service planners, commissioners and providers.

2.2 The involvement of patients and the public in the planning and management of services and in the issues of their individual care is an essential component of empowering people to engage in the co-production of health.

2.3 Furthermore, increasing patient engagement enables people and communities to take increasing responsibility for their individual and collective health.
2.4 The overall purpose of patient and public involvement must be to enhance the quality of services and to ensure that the provision of public services is shaped to the needs of patients, users and carers so that a more effective, accessible and equitable service can be achieved.

2.5 As consumers patients have a right to shape, choose and influence the services that they receive. Whilst NHS services are free at the point of delivery, the RCN believes that in a tax-funded service to members of the public, users of services and health care communities should have a robust means by which to influence and inform service delivery and planning.

2.6 It is the intention of government policy that public service provision becomes increasingly diverse. As a result the number of organisations providing health services will increase and the range of sectors from which they are drawn, (eg private, social enterprise and three sector organisations) will be extended. In these circumstances, the RCN believes that there is an ever greater need for patient and public involvement in monitoring the provision and commissioning of those services. Increasingly plural provision will require ever greater representation of public interests if it is to retain integrity in and the confidence of the communities being served.

What form of patient and public involvement is desirable, practical and offers good value for money?

3.1 The form of patient and public involvement adopted by public services is largely dependent on how providers and commissioners are required to engage with them. That requirement must apply across the whole of the respective public service. For that reason the RCN believes that the models being proposed within the Department of Health report “A stronger patient voice” may weaken rather than strengthen the representation and involvement of patients and the public.

3.2 Our primary concern is that whilst “A stronger voice” seeks to strengthen the voice of patients, carers and users in commissioning of services, it will do so by weakening that same voice in service providers. We are anxious that whereas the Patients Forums represented the views of groups and communities directly to provider organisations, the LINk groups that replace them will need to make their representations through a third party, the Oversight and Scrutiny Committee.

3.3 Any patient and public involvement should ensure that there is meaningful consultation with all areas of the community including those in minority groups or with special communication needs.

3.4 Given the complexity of health services, the ideal form of patient and public involvement will be one that is flexible enough to encompass a variety of different approaches whilst meeting the requirement to offer a robust and dependable form of representation. The RCN does not believe that one single model of involvement will suffice to encompass all that the ideal public patient involvement network will cover, given the requirement for health service organisations to offer meaningful consultation on service change and reconfiguration.

3.5 The RCN believes that only by providing a service which has the facility to meet those requirements for consultation as a minimum can any form of patient and public involvement be said to be desirable, practical and offer good value for money. Where expenditure is required from the public purse to cover the costs of judicial reviews or inquiries into the failure to consult, that form must be considered to be undesirable, impractical and poor value for money.

Why are Existing Systems for Patient and Public Involvement Being Reformed After Only Three Years?

4.1 “A stronger patient voice” says that a “strengthened system of user involvement” will be created, promoting “public accountability in health and social care through open and transparent communication with commissioners and provider”. Given our interpretation of the purpose of patient and public involvement (PPI) the RCN has concerns that this will not be the case and that existing systems of PPI have not been given sufficient time or resource to “bed in” effectively, nor has the model been fully evaluated.

4.2 Although the response to “A Stronger patient voice” has now been published by the Department of Health and we believe that the means by which it has been developed indicates one of the deficiencies of existing systems of consultation. The report itself was a “document for information and comment” and did not, therefore, constitute a part of a formal consultation process.

4.3 The RCN therefore considers that to reorganise the system of patient and public representation on the basis of a document of this nature is a missed opportunity to consult fully on an essential aspect of public service management.

How should LINks be designed, including:

5.1 “A stronger patient voice” indicates that there is variability in the levels of performance of existing representative bodies such as the Patient Liaison and Advice service (PALS) and patient forums. The RCN believes that research has demonstrated similar variability in the performance of Local Authority Health Oversight and Scrutiny Committees (OSCs). This indicates, in our view, a lack of evaluation of existing systems of consultation. The report itself was a “document for information and comment” and did not, therefore, constitute a part of a formal consultation process.

57 ODPM—The Development of Overview and Scrutiny in Local Government 17/10/02.
services and a lack of grounded research in the development of the new policy. We believe that if they are to be successful, LINks and their associated systems must be based upon grounded research and have the benefit of ongoing evaluation of their effectiveness in representing the interests, views and preferences of the communities that they serve.

5.2 Ultimately, the success of LINks will depend heavily upon the partnership between patients, carers, communities, practitioners and other health services staff. It is essential in responding to this report to emphasise that people who are employed in the provision of public services are, in themselves, citizens, members of communities and users of services. We are concerned that they, through the representation of their professional bodies and staff side organisations, continue to play an active role in the development of democracy in public services.

5.3 The RCN believes that whilst there may be a desire on the part of government to “localise” services which represent the interests of patient and publics, it is essential that they are designed around strong minimum standards that recognise their responsibility to ensure public representation in the process of service change, reconfiguration and development

Remit and level of independence

5.1.1 The RCN believes that any future model of patient and public involvement must have political teeth and a meaningful voice at local and national level. Staff working in health services need to be familiar with and have confidence in the new system in order that they refer patients and carers to its services. The RCN believes that positive experiences of the service should encourage future participation by individual and that the role which staff have to play in achieving this should not be ignored or their training in its application under-funded

5.1.2 The RCN does not support the current vision of LINks as the new mechanism for patient and public involvement because it adds layers of bureaucracy for no tangible benefit and has fewer powers than its predecessors. We are concerned that since the demise of Community Health Councils there has been a gradual watering-down of the powers of patient and public involvement networks.

5.1.3 In short, the RCN is concerned that rather than overcoming existing democratic deficits in the management of health services, LINks may exacerbate them and that the rapid reorganisation of public representatives in health services will reduce support from the communities they serve, whilst having insufficient authority to hold an increasing range of provider organisations to account.

5.1.4 We are concerned that if LINks and Oversight and Scrutiny Committees (OSCs) focus their attention primarily on the commissioning of services, there will be insufficient representation of patient and public concerns about provider organisations in an increasingly plural market.

Membership and appointments

5.2.1 The RCN believes that one of the most crucial factors in gaining the support and participation of communities and individuals in the LINk groups will be their relevance and perceived value in local communities.

5.2.2 If future models are to capture the imagination of the public and encourage active engagement they must be valued and have influence.

5.2.3 There is a need to find creative ways of engaging communities in patient and public networks. Lessons could be learned from the good work done by Local Government on encouraging broad engagement in local elections.

5.2.4 The membership of the LINk group should include all potential users, not just actual users of the service.

5.2.5 The RCN would like to highlight that healthcare professionals are members of the public and as such payers, service users and service providers. As such, we recommend that there should be public, patient and practitioner involvement in the shaping of health services. The practitioners could be engaged in these forums as expert witnesses or non voting members. Furthermore, nurses are front-line providers and can act as patient advocates, bringing experiences of many patients to such a network.

Funding and support

5.3.1 Whilst the Department of Health White Paper “A stronger local voice: A framework for creating a stronger local voice in the development of health and social care services” seeks to address the issues of independence, transparency, and engagement, it does so without acknowledging the prevailing political or social context. For these reasons we believe that a heavy onus will fall upon the organisations charged with developing LINk groups and Local Authorities to recognise and understand the organisational pressures and political features that apply in a health service which they do not control or fund. The RCN is concerned that they will not have the resources or experience required to do so.
5.3.2 By widening the breadth of health service issues that will be considered by LINks and OSCs, the Department of Health will be creating administrative and cost pressures in public services. Although there is reference in the report to a start-up fund for the development of LINk groups, there is no reference to the source of revenue funding for the operation of the scheme and any system which will seek to draw down funding from a NHS which is already facing many local cost pressures will only serve to redouble pressures upon managers, practitioners and services.

5.3.3 The RCN want to seek a commitment from the Government for a defined sensible and sustainable budget for LINks which ensure that they are able to function, develop and grow expertise, not just to meet up on a regular basis.

Areas of focus

5.4.1 LINks should have an open agenda which will enable representation of issues of concern from a broad range of patient and public interests. The LINk group should also have access to and the benefit of expertise from a wide range of organisations engaged in the provision, commissioning and management of health services including Institutes of Higher Education; Patient Interest Groups; Royal Colleges; and Trade Unions.

Statutory powers

5.5.1 We believe that the present powers of the OSC are sufficient to support their future role in representing patient and public interests. Increasingly, RCN representatives are working with OSCs to address issues of concern regarding the provision and commissioning of health services, however we are aware of variation in the systems and means by which OSCs operate.

5.5.2 The RCN are concerned, therefore, that LINks will need the facility of dedicated time and representation within the systems and agenda of OSCs if they are to effectively represent the interests of an increasingly diverse population across the full scope of their remit in health and social care. This is an issue that would need to be addressed within legislation if it is to be addressed effectively.

5.5.2 Furthermore, the RCN is concerned that in focussing too heavily upon commissioning issues, LINks will have insufficient power to hold providers to account and that there would be too many steps involved in addressing patient and public concerns regarding the services that they receive. This too is an issue that would need to be addressed within legislation.

5.5.3 Although we believe that the powers of OSCs are significant, as the bodies to which LINks would report their issues of concern, the RCN believes that patient groups need to have a system of empowerment. This would require, we believe, harnessing the powers of OSCs so that issues of dispute can be more easily resolved through arbitration at local level rather than being referred through to the Secretary of State and the Independent Review Panel. The RCN believes that the present system has become excessively delayed and discredited in the eyes of public and community groups.

Relations with local health Trusts

5.6.1 With patient and public representation no longer being hosted by nor having a direct relationship with NHS Trust, significant consideration will need to be given regarding the promotion of positive working relationships.

5.6.2 Without the facility of access to the Board meetings of NHS Trusts, LINk groups will need to develop a system for direct representation of issues of concern to NHS Trusts, like other provider organisations, so that matters of concern can be addressed and resolved at local level. The advent of NHS Foundation Trusts and the possibility of NHS Community Foundation Trusts, with separate systems of patient representation may limit the potential of LINks to address issues of concern with these organisations.

National coordination

5.7.1 The Commission for Patient and Public involvement in Health and its predecessor, the Association of Community Health Councils had a role in terms of national co-ordination and representation of patient and public issues and concerns. The future model described in “A stronger patient voice”, offers no similar service. The RCN is concerned that this will reduce opportunities for patient and publics to be represented in the development of national healthcare policy. The report mentions that “work is being undertaken to explore ways of creating a stronger voice for patients, service users and members of the public at national level”—the RCN believes that unless these issues are addressed, the new model has the potential to weaken rather than strengthen the system of representation and involvement of patients, users, carers and the public in health and social care services.
5.8.1 The RCN has no fixed views regarding the governance structures underpinning LINks groups but do believe that they should be suited to the needs of the local community, promote the principles upon which they are founded and that they are either funded through a ring-fenced budget or achieve cost-neutrality.

How should LINks relate to and avoid overlap with:

6.1 Local Authority structures including Overview and Scrutiny Committees

An informal or ad hoc relationship between the Local Authority OSC and LINk is insufficient. It is essential that LINk groups have dedicated time and facility within the working agenda and committee systems of Local Authority OSCs. Without opportunity to make formal representation on issues of concern to patients and the public, especially in matters of service reconfiguration and delivery, the potential influence of LINks would be diminished and democratic processes severely compromised.

6.2 Foundation Trust boards and Members Councils

It is important that members of Foundation Trust Board of Governors and Members Councils do not feel compromised by their need to adopt a “corporate” role in representing the interests of patients, carers and the communities that they serve. In that respect they should have ready access to their respective LINk so that they can ensure the concerns of individuals and groups are recognised and addressed by an appropriate service which is independent of the Foundation Trust.

6.3 Inspectorates including the Healthcare Commission

6.3.1 The Healthcare Commission is an inspector and regulator of services and there could be a conflict of interest appropriate mechanism for patient and public involvements in the NHS. If LINk groups are given the authority to inspect provider organisations, there is a potential conflict of interest regarding HCC and their ability to undertake unbiased consultation given their primary role as service regulators. Furthermore, their may be issues with the public’s perception of the Healthcare Commission undertaking both roles.

6.3.2 However, work from the Healthcare Commission could and should inform patient and public involvement eg the public should continue to have access to reports on providers, and might even be used to identify areas for patient and public consultation.

6.3.3 The RCN believes that further consideration should be given to extending the remit of LINks so that they can refer their issues of concern to the Healthcare Commission as the regulator of services?

6.4 Formal and informal complaints procedures

6.4.1 There needs to be clear and transparent mechanisms and processes for complaints to be made. However the RCN would like to highlight that complaints are only one way of involving patients. There should be other positive and productive methods of involving patients.

In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

7.1 The RCN believes that the circumstances as set out in section 11 of the Health and Social Care Act 2001 are appropriate and set out where public consultation is appropriate.

Royal College of Nursing
January 2007

Evidence submitted by the Royal College of Paediatrics and Child Health (PPI 19)

1. The main objects of the College are to advance the art and science of paediatrics, improve standards of medical care to children, and to educate and examine doctors in paediatrics. Additionally, the College has a function in providing information to the public on the health care of children.

2. The Royal College of Paediatrics and Child Health welcomes the opportunity to provide evidence for the above consultation. The College’s response was developed with input from Mrs Sally Carroll, Chair of the College Patients’ and Carers’ Advisory Group, and members of the PCAG.
3. The College welcomes this parliamentary review of patient and public involvement and consultation by the NHS in England. There are a number of important points that we feel the Committee should consider in its deliberations.

4. The College is concerned that the most organised and articulate groups representing the interests of patients with a specific condition can be influential on health policy and service provision to a degree disproportionate to the numbers they represent which can actually risk increasing health inequalities and relative neglect of groups of patients in great need of increased resources for their care. We would ask the Committee to consider practical ways to address this problem of inequality to ensure equitable attention is paid to the range of needs suffered by children and young people with different health conditions.

5. The College feels young people have a right to have a voice separate from that of adults and structures must be put in place to ensure this. Therefore, we suggest that young people’s focus groups, special young people’s committees or other appropriate groups should be set up and resourced to act as the PPI representatives for children and young people. In Scotland the Children’s Commissioner has set up just such a group although it is still in its infancy. 

6. The College is also aware that some service users feel that the current Patient Advice and Liaison Services (PALS) provided to them can be more concerned to give information and support than to work to change and improve services.

7. The College also wishes to bring to the Committee’s notice that there is an extensive literature on how children, young people and parents are frequently consulted but that little or no use is made of their responses and we would ask the Committee to ensure that at least as much time and funding is invested in implementing the findings from consultations as in conducting the consultations. We feel that those undertaking PPI should commission reviews of the research about service users’ (in our case children and young people’s) views and how they can voice their needs.

8. The Committee should also be aware of the increased dependence of many patients’ groups, as well as health professional organisations, on pharmaceutical companies for resources with the potential for consequent influence on the public statements and agendas of these groups and we feel that this is an area that should be scrutinised in the future.

9. This College is aware that the charity Contact a Family, with which this College works closely, is also to submit evidence to the Committee and we wish to specifically endorse the following points that are made in the Contact a Family submission.

10. The College wishes to point out the position of parents of children with long term disabling medical conditions and that it is these parents, who are regular health service users, who are least likely to have time to get involved with ongoing participation as much of their time is taken up in caring for their child. Moreover, the College would add that there needs to be appropriate mechanisms for ensuring the voices of children and young people with long term medical conditions are heard.

11. It is not possible for one small group of individuals to be able to represent all the different groups who use health services. Patients who want to get involved with participation are often motivated to do so as a result of their own personal experiences. For example, the parents of a disabled child might be motivated to get involved to improve services for other disabled children with similar health problems but be less interested in committing personal time to improving services for another section of the community yet clearly Local Involvement Networks (LINks) need to be able to consider all aspects of local community health services. The members of LINks should therefore not try to represent all patients views, but facilitate a process whereby patients’ experiences are fed back to the appropriate strategic committees and where necessary action taken to address problems. LINks should have the flexibility to co-opt individuals to work on particular projects. Voluntary organisations and community groups are often aware of what difficulties their members have in accessing services. They can also provide a mechanism through which service users can feedback their experiences of services anonymously.

12. Provision of training is required to ensure commissioners, members of LINks, and local community groups understand how to make participation work effectively.

13. The College also wishes to present as evidence to the Committee the response produced by this College to the recent Department of Health consultation document A Stronger Local Voice: A Framework for Creating a Stronger Local Voice in the Development of Health and Social Care Services. This two page document is included with this submission to the Health Select Committee.58

Dr Hilary Cass
Registrar, Royal College of Paediatrics and Child Health

9 January 2007

58 Not printed here.
Evidence submitted by The Royal College of Radiologists (PPI 50)

The Royal College of Radiologists

1. The Royal College of Radiologists (RCR) has approximately 7,000 members and Fellows worldwide representing the disciplines of clinical oncology and clinical radiology. All members and Fellows of the College are registered medical or dental practitioners. The role of the College is to advance the science and practice of radiology and oncology, further public education and promote study and research through setting professional standards of practice. The RCR currently has two Patients' Liaison Groups (PLGs), one for clinical radiology and one for clinical oncology, and a lay representative on its Council.

2. The RCR recognises the importance of patient and public involvement (PPI) and has benefited enormously from the work of the PLGs in the past. They are involved in all new initiatives and we are intending to build on our current structures to find ways of enhancing and maximising their involvement. To this end the College has recently commissioned a project to review the future development of patient and public involvement (PPI) in the work of the College, with recommendations to be outlined by July 2007.

3. The aim of the project is to consider patient and public involvement and engagement within the RCR and to raise the public profile of the College. This includes reviewing current arrangements and developing a strategy for the future. It should ensure that the proposed framework for patient and public involvement within the College is fit for purpose and fulfils the RCR objectives of patient involvement, which are:

- To provide a patient and public perspective on all aspects of the activities of the College
- To meet wider patient and public expectations
- To raise the awareness of the work of the specialties and the College with the public
- To increase the political and professional influence of the College
- To fulfil wider educational aims.

4. The remit includes looking at the topic from a wider perspective, such as:

- Considering the overall framework and structures of patient involvement in the work of the College
- Using patient representatives to raise increased awareness of the two specialties and the profile of the College with the public
- Recognising that at times the two specialties may benefit from different approaches to patient involvement
- Raising the awareness of Fellows and members to the value of lay representation.

The review may also look at more specific issues around involvement of patient representatives within the College, for example, recruitment methods, frequency of meetings, time commitment, resources, administrative support and means of broader patient consultation.

Response

What is the purpose of patient and public involvement?

5. It should be a fundamental tenet of organisations that those paying for a service and those affected by it have a moral and ethical right to be engaged in its design and development. Public and patient involvement should be necessary for decisions as to what services are provided, how they are provided, quality setting and monitoring and the maintenance of standards. A service can only be responsive to users if users are involved. PPI offers service providers and commissioners the opportunity to better understand the needs of patients.

6. PPI has never been more important than it is now, at a time of reconfiguration and when crucial decisions are being made by commissioners which impact on local services. If providers are to purchase services on behalf of taxpayers it makes sense that commissioners talk to them about the services they buy and forge relationships with them so as to increase their knowledge about the quality of the services for which they pay.

7. Responsibility for healthcare has come increasingly to be seen as a partnership between professionals and patients, with professionals becoming more publicly accountable. Engaging patients in health policy decision-making helps to ensure that policies reflect patient needs and preferences, and this must ultimately make for more effective healthcare. In a publicly funded health service, this serves to increase accountability.
8. The term patient and public involvement encapsulates the two streams of lay involvement in healthcare services. Patient involvement is the contribution of individuals to their own healthcare, and public involvement the participation of individuals or groups in the development, planning and provision of services.

What form of patient and public involvement is desirable, practical and offers good value for money?

9. Involving the patient and publics is not straightforward. People as individuals and within groups can have diametrically opposed views. Commonly excluded groups such as those with language difficulties, learning difficulties, disabilities and those without the time available to commit through traditional means of involvement need to be reached. Once involved, it is important that people do not become distrustful of the process. This can happen if their participation is not acknowledged, or what they contribute does not appear to make a difference or at least be considered. Involvement must not be tokenistic.

10. PPI structures should exist at all levels throughout the healthcare system and should be used to feed both up and down into decisions relating to the design and development of services and to the commissioning of services. Decision-makers should also be required to demonstrate how they have incorporated and responded to the views of those with whom they consulted. It is important to ensure appropriate training, resource and support structures are in place to ensure effectiveness.

11. Professionalising of PPI may lead governments and providers to regard only the views of a national organisation or their locally trained patient advocates because they “represent the patient view”. This would be detrimental to PPI. People who do not belong to a patient organisation would not have a voice. The terms of reference for the inquiry do not appear to give consideration to the many already existing Public and Patient Fora, which do valuable work, and have direct influence, albeit in more restricted fields.

How should LINks (Local Involvement Networks) be designed?

12. Representation, capacity and resources are key elements in enabling LINks to work. The task of collecting real public opinion can be complex and time-consuming, particularly if it is to be done properly. Therefore, LINks must have the capacity and resources to be able to undertake their duties. Representation would ideally reflect the population, but more important will be the ability of LINks to reach all the constituent parts of its population served, including those traditionally excluded.

13. There is a danger that LINks may be too closely allied to local authorities to be independent of local politics and any conflicts of interest that may arise. There may also be conflicting views within LINks because of the size of areas covered and the priorities of particular localities.

14. However, a smaller number of organisations may mean more capable people are available for recruitment to LINks. It is important that LINks have the power to refer matters to Overview and Scrutiny Committees and to inspect providers’ premises. It is also vital that LINks have the appropriate funding to carry out their role.

How should LINks relate to and avoid overlap with Local Authority structures including Overview and Scrutiny Committees etc?

15. As stated above, it is important that LINks have the power to refer matters for consideration to Overview and Scrutiny Committees (OSCs) and that OSCs use LINks to inform their work in reviewing local health and social care services.

16. It is also important to consider how LINks relate to other bodies such as non-Foundation Trust boards, private sectors of the Health service, patient and public representation on many medical/clinical bodies such as BMA, medical Royal Colleges, Cancer networks etc.

In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

17. Any attempt to use consultation as a tool for gaining public views should provide open and transparent information. It is also important that appropriate timeframes are given to consultation as, for individuals or unsupported groups, tight deadlines can give little scope for deep consideration or understanding.

The Royal College of Radiologists
4 January 2007
Evidence submitted by the Royal College of Surgeons of England Patient Liaison Group (PPI 85)

Summary

— The Patient Liaison Group is well supported by the College
— The workload for the group is high and has to be prioritised. Not all requests for input can be met. This seems to reflect experience of other patient and public involvement groups
— Public consultations should be live for a minimum of 12 weeks

Brief Introduction to Patient Liaison Group (PLG)

Membership is made up of twelve lay people and six surgeons, with two other ex officio surgeons. The lay chair is an invited member of College Council. The Group has a full-time administrator funded by the College, access to advice from other College staff and is able to link with the President as required. Lay members are recruited nationally via the press and formal interview. They have direct extensive experience of being surgical patients, family carers of surgical patients and/or membership of patient organisations. Maximum membership of five years ensures regular new members but is long enough for members to develop extensive knowledge of College work and of health policy.

Lay members represent the Group on approximately 35 other committees and working parties, inside and outside the College. The Group is strongly supported by its surgical members who provide extra insight into the NHS and advice. The Group frequently responds to consultation documents, both under its own name and as contributions to College responses. It develops some of its own work to further its aims, for example a review of research into communication skills and a forthcoming guide to help surgeons improve their patients’ journeys. It belongs to and works with the Patient Liaison Group of the Academy of Medical Royal Colleges. It produces a bi-annual newsletter as an information link and source of feedback between the Group, patients and the College membership.

Factual Information for the Committee to be Aware Of

The workload for the Patient Liaison Group is high. The lay and surgical members all have limited time to deal with topics that are complex, fast changing, can require extensive liaison with the College and all against a keen responsibility that we must contribute our voice and often challenge directly, for example the recent decision to drop clinical and communication skills examination from the intercollegiate MRCS. The Group could not manage without its full-time administrator and is aware that other royal college groups don’t always have equivalent support. The Group works to an annual forward plan and increasingly has to prioritise work as it cannot cover all possible topics and request for input.

Despite the skills and resource available to the Group, six-week consultation exercises are almost impossible to manage. The Group has had to inform NICE that it cannot respond to their one-month consultations except in very high-priority circumstances and it has had to leave individual members to respond to NICE if they wish.

Members who are also involved with Patient Forums report similarly high workload and in addition, unlike the RCS Patient Liaison Group, have difficulty in recruiting members.

Recommendations for the Committee to Consider in Its Report

1. Remit and Level of Independence

   1.1 The independence of LINks should be incontrovertible.
   1.2 We believe professional support of the type provided to CHCs would provide increased effectiveness and a greater reassurance of independence.

2. Membership and Appointments

   2.1 The PLG wants to be able to use information from LINks to help ensure its own work is representative. LINks work must be easily available via a website which identifies the difficulties in undertaking the work, not just the successful outcomes.
   2.2 We require reassurance that information and recommendations from PPI work in trusts and LINks has been collected objectively by LINks or NHS staff with enough training and resource to follow appropriate methodologies.
   2.3 We want to know that LINks will represent not just “hard to reach groups” but the general body of the public which doesn’t fit this category but is still hard to consult and involve. We want reassurance that LINks can prioritise work according to LINks’ view of importance, not because of lack of volunteers, effective support for volunteers or training.
3. **Funding and Support**

   3.1 There needs to be a greater recognition nationally of the amount of work the changes in healthcare are requiring of volunteers and of the support they need.

   3.2 Any organisation supporting LINks must have extensive understanding of the NHS and be recompensed for their knowledge and experience as well as being appropriately funded.

   3.3 Despite the reassurances contained in the Government’s response to “A stronger local voice” about the protections around funding, concerns remain that funding will not be ring fenced. The recent example of SHAs using medical training funds to reduce debt, increases such concerns.

4. **Statutory Powers**

   4.1 The recent reassurance that existing statutory powers will continue is welcome as is the acknowledgement that high quality training is essential before such powers are used.

5. **Relations with Local Health Trusts**

   5.1 LINks should be able to review and report NHS PPI work independently and comment on Trust submissions in the Healthcare Commission Annual Healthcheck.

6. **National Coordination**

   6.1 All consultations should be live for a minimum of 12 weeks.

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**Liz Symonds**
Chair, Patient Liaison Group of the Royal College of Surgeons

10 January 2007

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**Evidence submitted by the Shaw Trust (PPI 127)**

Shaw Trust is a Not for Profit Organisation that currently supports 49 Patient and Public Involvement Forums in North East Lincolnshire, North Lincolnshire, Lincolnshire, Norfolk, Suffolk, North East London, Mid London and South East London.

1. The purpose of Patient and Public Involvement (PPI) is two-way: it is to independently inform Health and Social Care authorities of needs for and public perceptions of health services, and to help communicate to both patients and the public the decisions made in Health & Social Care and the reasons for them.

2. This will include stimulating community action and helping instigate changes in service provision and planning; seeking and using the community views and contributions; engaging people in all levels of decision making; and identifying opportunities for community development.

3. What form of PPI is desirable, practical and offers good value for money? The notion of “sustainability” is essential to PPI. Most people are wary of government initiatives, which fluctuate, and individuals must be encouraged to understand that their personal participation is essential. The public & Patients must be allowed to define “success” and what it means to their community. In addition what must be recognised is consultation overload, ensuring that it reaches all groups/diversities.

4. Due recognition should be given to the volunteers who work tirelessly to make the NHS relevant to the community it serves and the expertise of those who have acquired many years experience must be incorporated.

5. As we live in a multi-cultural society we have diverse lifestyles and beliefs. Our communities are geographical groupings, but they are also communities of interest and we belong to more than one. All PPI must include local people/organisations including socially excluded groups but these need to feed into a national voice on larger issues.

6. There must be the creation of effective partnerships between all the agencies. In other words it means the involvement of statutory, voluntary agencies, local communities and individuals in the business of health care in our communities. The involvement should be co-evolving and sustainable.

7. The question as to why are existing systems for PPI being reformed after only three years is for the Ministers to answer as any response can only be second-guessing. From feedback we have accumulated the views are that the Commission for Patient and Public Involvement in Health (CPPIH) has been inconsistent, with its approach varying from region to region. During their contracting and tendering process with Forum Support Organisations (FSO) there have been questionable approaches, and appointments with inconsistencies within FSO contracts. The Forums views have been that the approach CPPIH took lacked
credibility. In addition, many Forums were hampered in the beginning by poor support and are only finding their feet now, as they are about to be disbanded. The feedback also suggests the Forums perceived a lack of respect for their contributions without giving them time to get established.

8. There is a lack of knowledge nationally on what Forums do and what their role is. There are barriers within the NHS to PPI and a culture of tick-box standards.

9. In some areas Forums are not seen as engaging with their community but merely addressing personal issues.

10. How should Local Involvement Networks (LINks) be designed? LINks should be seen as independent of the NHS and local government providing a pathway for true consultation and participation. By being independent the culture within Health & Social Care would need to change to recognise patients as clients and to give credence to the clients viewpoints.

11. LINks should be widely promoted to give them credibility and status and thereby encourage participation. LINks should capitalise on good practice from the Forum experience.

12. Serious thought is required in regard to Mental Health, Ambulance Services and National Institutions, all of which span multiple Boroughs and therefore will not be served by the LINks system as currently outlined.

13. Membership & Appointments. LINks needs to encompass all people and groups as all views are essential. Every effort should be put in place not to create barriers to inclusion. All diversities need to be addressed, along with the recognition that there are many ways to involve people all of which do not necessarily include an application process. PPI has been around through Community Health Councils and Patients Forums with volunteers having gained huge experience and expertise which would be essential to a future participation.

14. Statutory powers. As an FSO and through Forum feedback we feel there is valuable merit in regard to patient experience in continuing the rights of inspection and monitoring and it gives people tangible involvement rather than purely a strategic input. Volunteers need to be valued and need to achieve targets. Do not make LINks so strategic that people are scared to become involved due to perceived lack of understanding.

15. Inspection and monitoring also contributes to helping Patients Forums feedback in the Healthcare Commission Annual Health Check.

16. Equally important is the right to a response. LINks should be able to ask a question of a Trust or Strategic Health Authority and expect a response as the NHS is publicly accountable. In addition to the right to response is the right of referral to pass on findings for further investigation.

17. Funding & Support. Finance while it has been stated that monies (amount unknown) will be made available to Local Authorities to procure support services (Host) to LINks, it is seen as a shattering arrangement removing the possibility of consistency, and of a regional / national picture with 152 different ways of delivering, duplication of service and a fractured approach. PPI must finally be taken seriously and funded accordingly.

18. Any Host organisation must be financed fairly. A major complaint has been that FSOs were not paid the same by CPPIH to deliver the same service resulting in widely differing standards of support.

19. Performance management of the Host must be taken into consideration as to by whom and how this would happen. Are we likely to see 152 different standards nationally dependant on who has the task in the Local Authority? This is currently the experience with Trusts and PPI as the level of expertise is dependent upon the grade of the position.

20. Relations with local Health Trusts. With Forums this can only be described as variable dependant on the Lead for PPI, the attitude of the Trust Board or Forum personalities. For there to be effective involvement, there must be a partnership, with a clear understanding of the purpose and role of a LINK and it not being seen as an interference. The culture within the NHS must change to appreciate what PPI can offer and not treat it as a tick-box exercise. Client feedback is essential to any successful operation.

21. National Co-ordination. Whilst it could be perceived that CPPIH failed at this role it does not mean this model does not work. There are several facts that need to be taken into consideration including governance—appointment; membership; guidelines; code of conduct; complaints and performance management. The ability to feedback on national and regional issues; The need to have a centrally controlled IT system.

22. Local Authority and Overview and Scrutiny Committees (OSC). Firstly not every Local Authority has a specific health OSC. It could be seen that the OSC is a political body and not necessarily representative due their own political agenda. There could be difficulties to maintain continuity of work due to elections. As OSCs do not have the right of inspection there is a clear role for partnership. However, there is potential for conflict of interest where focus groups are funded by local contracts which could nullify the all-important independence.
23. Healthcare Commission. To date Patient Forums have formally been involved in the Annual Health Check. This has been seen as valuable to the Healthcare Commission, which could indicate that LINks could equally contribute as Lay Assessors in the inspection process.

**Kirstine Regan**
Shaw Trust
10 January 2007

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**Evidence submitted by Sheffield Children’s Hospital NHS Foundation Trust PPI Forum (PPI 52)**

I have been a member of this Forum since it started and during the last three years we have worked with the following groups:
- Primary Schools
- Secondary Schools
- Local Surestart and Children’s Centres
- Family Service Unit
- SIGN (an information centre for disabled children, young people and their families)
- Northern Refugee Centre
- Oral Health Promotion Unit
- SHINE (Self Help Independence Nutrition and Exercise)
- Somali Mental Health
- Travellers Health Group
- Healthy Cross Initiative
- Various support groups for parents/carers of children with special needs, Alder Hey, Great Ormond Street and Birmingham Children’s Hospital Forums (regular meetings)

We also spend time in the hospital talking to patients and parents about any concerns they may wish to raise with us.

One of our members attends the Trust Board meetings, and we have one member on the Diversity and Involvement Committee of the hospital, and have close links with the PALS service and management team. We also work with the Child and Adolescent Mental Health Teams in Sheffield as this service is part of the Trust’s responsibilities. One member sits on the Children and Young People Scrutiny and Policy Development Board at Sheffield City Council which scrutinises all aspects of service provision for young people in the city.

— Our members feel that the work we do does not fit within the remit of local involvement as acute trusts have their own board and executive who have been appointed for their ability to manage their organisation particularly in the case of specialist children’s hospitals where patients travel from all areas of the country.

— The 500 responses to the consultation by the Department of Health did not indicate any real interest from the public. 50% of the 500 responses were from PPI forum members, 14% from NHS staff, 13% from Local Government, 13% from Stakeholders, 4% were unspecified, 1% each from FSO staff and Trade Unions and 2% each from MPs and members of the public. Given the difficulty CIPPHE have encountered in recruiting and retaining members even with their large budget this 2% does not look like a demand for greater involvement from the public.

— There has been no formal review to ascertain what the problem—if indeed there is one—was with the existing forums

— Our Forum already does exactly what the Department of Health says it wants LINks to do but without the budget and autonomy we now have although our focus is only on children rather than all social services and health care within a local area.

— We have succeeded despite having only four active members during all of the previous three years

**Alice Riddell**
Vice Chair, Sheffield Children’s Hospital NHS Foundation Trust PPI Forum
9 January 2007

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**Evidence submitted by the Socialist Health Association (PPI 123)**

The Socialist Health Association was founded in 1930 to campaign for a National Health Service and is affiliated to the Labour Party. We are a membership organisation with members who work in and use the NHS. We include doctors and clinicians, managers, board members and patients. Our interest in patient and public involvement is longstanding. Our members campaigned for democracy in the NHS in the 1930s and 1940s and for the establishment of Community Health Councils in the early 1970s. Many were CHC
members and many are now members of patient forums or act as lay members on various bodies including both the GMC and local pharmacy committees. Our members are involved in a wide variety of consultation and involvement processes in health and social care. This submission is made on behalf of the Association.

1. What is the purpose of patient and public involvement?

There are many possible answers to this. And or course there are many sorts of involvement at different levels and for different purposes. We would hope the committee are familiar with Arnstein’s Ladder of Citizen Participation.59 We would like to see less tokenism and more citizen control, to use Arnstein’s typology.

Firstly there seems to be good evidence that in a more diverse society it has become difficult for healthcare providers to devise services which are appropriate for all sections of the community without explicitly involving them in planning the provision and ensuring that effective mechanisms exist to communicate their concerns and experiences of services. The second answer is that citizens are entitled to have a voice in the expenditure of large sums of public money on their behalf. Existing systems of local democratic accountability are grossly inadequate. PPI might not be so necessary if there was sufficient local democratic accountability. “Our public realm needs structures and strategies that can enthuse and empower every individual and every community to participate.” (Involve). For any organisation providing services to the general public, whether government owned, a voluntary organisation, or a commercial enterprise, it is vital for its success to have its performance constantly reviewed by its users. At a collective level, it is about patients being involved in designing new services and improving current ones. At an individual level, it is about shared decision-making. Because of the difficulty of getting informed responses from many patients (because of their condition) the involvement of a robust, knowledgeable and independent public & patients organisation is a necessity. Furthermore health is not a commodity to be purchased or just a service to be passively enjoyed. People need to be positively and actively involved with their own health and this requires opportunities for both collective and individual involvement. There is widespread evidence that the information component of healthcare in the UK is the part which is least effectively delivered and improving this requires active patient involvement.

2. What form of patient and public involvement is desirable, practical and offers good value for money?

The idea that PPI structures should relate to an area, rather than to specific healthcare institutions seems sound, but there will some operational complications: if the LINK for Cumbria, for example, wanted to investigate services for premature babies then those services are largely provided in Manchester and Newcastle. Some of the PCT areas are now very large and there will be considerable difficulty in organising face to face meetings for people across, for example, the whole of Devon. It will be necessary to facilitate arrangements whereby all the communities which use a particular service can be brought together. The network of LINKs will need to spread out beyond the area of an individual LINK.

PPI structures need to relate especially to disadvantaged sections of the community. They must be given the means to relate to people with sensory or language difficulties, people with dementia and those confined to their home or to an institution. It is particularly important that they can reach those who have more than one disadvantage—elderly Asian ladies for example. This probably means that they will have to work with voluntary organisations who will have the right contacts.

The blocks at the shared decision making level are partly to do with doctors/clinicians. Clinicians need incentives and training to get better at supporting patients in making more decisions themselves and caring for themselves better. Patients do actually find this quite difficult territory, too. The system does not incentivise people on the ground to make use of PPI. If it was monitored vigorously, if it really involved local people on the ground, if it was structured to make a difference, it would work much better—it could change the face of the NHS. The solution for both doctors and patients is to acknowledge the truth that nobody can look after anybody-else’s health, and, whoever you are, your health is your own responsibility. This is the message in the Expert Patients Programme course. Liam Donaldson, the Chief Medical Officer has rightly called for it to be provided for all the 17 million chronically ill patients in Britain. However, doctors are resisting it as they see it as the end of their ability to dominate their patients. Historically, doctors have had a monopoly on their knowledge of diseases. They have guarded this jealously as their stock in trade which gave them power over their patients. However, with the growth of the internet and complementary and alternative therapy, their monopoly is breaking, and many patients are now more knowledgeable than their doctor on their particular condition. The development of self care requires from clinicians:

— to trust the patient;
— a new way of handling consultations;
— a new way of handling their practice; and
— sharing power.

It is not clear at present whether equalities legislation applies to the activities of organisations like Patient Forums which are composed of volunteers. We think that it should, but there are clearly resource implications if people with for example sensory disabilities or lack of English language are to be fully involved. This would require not only, for example, money to pay for interpreters or personal assistance, but also training for those not so disadvantaged in how to work with these communities.

It is very hard to demonstrate value for money because of the difficulty of connecting outcomes to processes and structures. The Department of Health apparently spent £1 million on the “Your Health Your Care Your Say” process, and this does seem to have reached people who are not often involved and been regarded as a success, but we cannot expect resources on that scale very often. Involving people from very disadvantaged groups—deaf people for example—can be very expensive, but the most disadvantaged people are exactly the people whose voices need most to be heard. It would be helpful if the Government could clearly define what it wants the system of PPI to deliver. Without this there is no means to judge if the system fails. If such a definition can be produced then we suggest that arrangements should be made to review the operation of the new system in five years time, by which time it should have had an opportunity to prove itself.

A great deal of money is presently spent by individual NHS institutions on one off consultation processes. Often the outcome is predetermined and the consultation is a waste of time and money. Often there is little useful information provided (especially about money) and the consultation documents are bland and evasive if not downright dishonest.

We would argue that PPI structures need to demonstrate first independence and second continuity. We deal with independence below. Continuity should extend in time, in personnel, in place, across institutional boundaries, and across communities. What is needed is a mechanism which can connect communities of various kinds to the decision making structures and which transcends institutional boundaries in a way which provides resources independent of the interests of the various institutions. Only small numbers of people will have a continuing involvement with these mechanisms but there need to be ways for the wider community to raise concerns and to enable communication with the public. Organisational stability is important for structures largely populated by volunteers. It requires a considerable input of time and effort by lay individuals to begin to comprehend the NHS. It is particularly important for the PPI organisations to have a collective memory given the transient nature of many health organisations and this is largely provided by the employment of professional staff. We would like to see some investigation of differing practices in Scotland and Wales to see if lessons can be learned across the national boundaries.

3. Why are existing systems for patient and public involvement being reformed after only three years?

Because Ministers like to give the impression they are doing something, because the systems they established in England in 2003 have not been very effective and because it is now quite clear that the abolition of English Community Health Councils was an expensive mistake. Regardless of the reason for this change we hope that more will be taken over the process this time. It is important to retain the skills and experience of staff and volunteers and the records of organisations. We see no reason why CHCs could not have been reformed, nor why Patient Forums have to be abolished when they also could have been reformed.

4. How should LINKs be designed?

Remit and level of independence

The remit of LINKs should extend to health and its wider determinants, as well as health and social care. If LINKs are not perceived to be independent they will have no credibility. Under the present proposals the most obvious threat to their independence is their relationship with the sponsoring local authority who will be responsible for managing the contract under which the support staff are to be employed. Experience tells us that some local authorities are capable of manipulative behaviour when local political interests are involved. Under the CHC regime it was not unknown for voluntary organisations’ funding to be threatened if their representatives did not vote the way the local council wanted them to. It is therefore important that the process of managing the contract is protected from political interference by establishing a transparent process and a fixed timetable—we suggest contracts should normally last for five years and any change should be agreed by the LINK, and not just by the local authority. As an additional safeguard, the contract should not be awarded to any existing group which enjoys major funding from the local authority concerned.

Membership and appointments

It is not clear what is meant by membership of a LINK organisation, given that there are to be both individuals and organisations in membership. The Department of Health envisage a LINK as a network. For many purposes a flexible participative process will be necessary and desirable, but there may be times when a decision will have to be made about which there will be different points of view. It may be necessary to define a core membership in order to permit democratic decision making. We would suggest that there should be a requirement that every person who participates in the work of a LINK should be required to...
be normally resident in the area of that LINK (although of course the work of a LINK may lead to investigation of services provided for their residents by organisations many miles away). We would not want to see a system whereby people represent organisational interests as a member of a LINK nor any kind of block voting system.

It may be better to accept that membership is entirely voluntary and self selecting rather than to establish some sort of vetting body which has been a source of substantial problems for Patient Forums. This would mean that the collective voice of a LINK would only have more weight than the voices of the individual members if it could demonstrate wider involvement, particularly of disadvantaged groups, or enhanced expertise. In reality the response of a LINK to many consultation processes will be based on the experience and knowledge of its members. There will never be sufficient resources to involve the wider public and the most disadvantaged people in every issue. We suggest that if LINKs make official responses they should be required to state what processes informed the production of that response. We would envisage that all lay people who have any sort of representative role in the arrangement of health or social care services in the area would automatically be a member of their local LINK.

It is important to recognise the increasing diversity and fluidity of the voluntary sector if these organisations are to be brought into LINKs. Many voluntary organisations will have financial interests in the provision of services in their area and it is important that these interests are declared and that these interests do not contaminate the voices of voluntary organisations representing their communities. Under previous legislation NHS employees and contractors were not allowed to be members of CHCs or Patient Forums. If such a prohibition is to continue then it should probably extend to any person with a financial interest in the provision of health or social care services in the area of the LINK. If the prohibition is abandoned then there will need to be a mechanism to register the declaration of interests. It will be very important that LINKs adhere to the Seven Principles of Public Life established by the Nolan Committee and it will be necessary to ensure that there is some mechanism for dealing with complaints about this. There may be lessons to be learnt from the experience of the Standards Board for England.

We think that there is considerable potential for using internet based mechanisms for collecting the experience of patients, helping people to communicate with each other and to enable, for example, people who are housebound to participate.

### Funding and support

LINKs need to be in a position to employ professional staff with experience in community development and of how the NHS and social care work. They will also need people with good IT skills. It may be helpful for one organisation to support several LINKs, or for specialist organisations to deal with particular aspects of the work over a wide area. There needs to be organisational stability and a career structure if highly skilled staff are to move into this work. The staff should be accountable to the LINKs whose members should be involved in any appointments.

We would want to see a very transparent funding regime. On balance we think funding should be directly related to population and not weighted for deprivation, rurality or any other factor. If there is a national budget of say £25 million for the population of England that works out as approximately 50 pence per head per year. Such a simple formula would make it easy to see whether the money is reaching its intended destination. We suggest that if it is thought proper to make specific funding provision for particular sorts of deprivation or activity that this should be provided separately. We do not see that it would be possible to produce a formula which would take account of all the different factors which might make involving people in a particular area more expensive than the average. We see no reason why service providers or commissioners should not pay LINKs to conduct consultations or other projects on their behalf just as they often pay freelance consultants now, although we might need to ensure that the independence of the LINK was not compromised.

### Areas of focus

We would wish to see LINKs have a wide remit to deal with all sorts of health and social care topics in their area—including all those issues which affect the health of a population but are not the direct responsibility of the NHS.

We would envisage LINKs as having a particular role in fostering the development of local involvement mechanisms, in particular localities, among particular communities or with individual practices or providers. This should certainly extend to an involvement with Practice Based Commissioning which up to now has had little patient involvement.

### Statutory powers

We consider that LINKs should in themselves have some statutory powers over and above the powers available to the public in general. The main legislative change needed is to give PPI representatives more power. They need statutory rights to sit on, speak and vote on all NHS committees concerned with patient care. Patient representatives need support in what is a tough job. On each committee there should always
be establishment for at least 2 patient representatives, so that they can support each other. If for any reason a PPI rep cannot be present at any meeting, they should have power to appoint a deputy or a substitute so that there is never a vacant chair.

In addition we would want each LINK to have access to the detailed terms of any contract for the provision of health and care services to people in its area. We understand that there will be objections to this on the grounds of commercial confidentiality but in our view openness is part of the price of undertaking publicly funded work. We would have no objection to some provision making commercially sensitive information subject to confidentiality for a limited period. We think that the proposal to give nominated LINK representatives rights of access to health providers premises on the basis that only those nominated will have CRB checks is a sensible compromise, and that right of access should extend to any provider of services.

One problem which may inhibit the relationship between patients and a LINK is the existence of the systems to regulate medical research. We would wish it to be made clear that enquiries made to competent patients who are capable of understanding by a LINK about their experience of health and social care services does not constitute medical research and does not normally require ethics committee approval.

Relations with local health Trusts

If the NHS is truly going to embrace diversity of provision then we would want to see LINKs relate primarily to the commissioning bodies and for their remit to embrace providers of all sorts. This will clearly include existing NHS Trusts and these Trusts may not necessarily be located in the area of the LINK. The remit of each LINK should relate to the services provided to people resident in their locality, wherever those services are provided. We would expect NHS Trusts to establish positive relationships with local LINKs but in our experience these relationships need effort from both sides. We are glad to see that effective PPI skills are beginning to be regarded as important to NHS managers. We would expect a LINK to establish a group to relate to each significant provider of services for its local area.

National coordination

A national and regional organisation will be very important for the success of LINKs, and the lack of it has contributed to the weakness of Patient Forums. However the national and regional organisations must be answerable to the local LINKs, and not the other way around. Members of LINKs must be enabled and encouraged to communicate with each other across the country so that specialist issues can be addressed. Development of standards of conduct for LINK members for example should come from the bottom up. We would envisage mechanisms whereby representatives of patients of all kinds, including voluntary organisations, at regional and national level would relate to these bodies. We also hope to see the emergence in due course of regional and national leadership capable of expressing the patients' voice and of coordinating and directing campaigns relating to patients experience so that if some future Secretary of State wants to declare that the NHS has had its best year ever there will be a credible patient voice able, on the basis of evidence, to confirm or deny such a claim.

5. How should LINks relate to and avoid overlap with:

Local Authority structures including Overview and Scrutiny Committees

In our experience Overview and Scrutiny Committees' effectiveness in relation to health varies very widely according to local political and geographical circumstances. We would like to see measures to bring more of these committees up to the standards of the best, and often this is down to the nature of the officer support provided. We would not want to see the effectiveness of a local LINK impeded by a local authority structure which is determined by its own political interests but we do think that there is potential for LINKs and Scrutiny Committees to work together constructively. However in some local authorities the Scrutiny Committee is incapable of providing an effective challenge to service provision of indifferent quality.

Foundation Trust boards and Members Councils

As yet the impact of the democratic arrangements for Foundation Hospitals is difficult to assess, but most of those involved report that as members or governors of a Foundation Hospital they perform a purely decorative function... There is clearly potential for using those mechanisms to improve consultation and involvement of patients with hospitals and this may be useful for the relatively small number of people whose care is delivered primarily by a hospital. We would expect Members Councils to relate to their local LINK. However the central political problem in health is the excessive political power and visibility of hospitals, particularly acute hospitals, as opposed to the invisibility of primary and community services.
Inspectorates including the Healthcare Commission

The efforts the Healthcare Commission and CSCI have made to date to involve patients in inspection arrangements are very encouraging and merit further development. We see the Commission as a powerful ally in the development of involvement and we want to see this role strengthened. We would like to see other bodies with inspection rights emulate their approach. LINKs should be recognized as working alongside the professionals in providing lay members for formal inspections. We would hope to see LINKs developing an independent voice for patients who may want to raise concerns different from those developed by official bodies. We also see LINKs as able to react much more quickly to local problems and much more able to deal with problems which cross institutional boundaries.

Formal and informal complaints procedures

The separation of complaints work from the work of patient forums has been a source of weakness as compared to the regime of the best CHCs where complaints contributed to a detailed picture of the performance of local health services. We understand that there are concerns about the confidentiality of complaints procedures but we consider that some mechanism must be devised to ensure that local LINKs (or possibly some designated committee of a LINK operating on a confidential basis) has access to information about complaints which is sufficiently detailed to enable LINKs to know which specific services give rise to complaints. There may also be a role for LINKs to protect patients who complain as there are still widespread allegations of victimization.

6. In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

The proposed amendments to what is now section 242 of the National Health Service Act 2006 appear to envisage much more general consultation than has previously been required, and we welcome that. We hope that the shameful practice where changes required to be introduced by the Department of Health are excluded from the duty of consultation will now cease. However it will clearly not be possible for every change to be subject to substantial and expensive consultation exercises. We would like to see decisions about the arrangements for consultation under section 242 taken locally in conjunction with the local LINK which could take into account a wide range of factors, including the capacity of local communities to respond and the relative significance of various proposals. We would certainly like to see the end of the ritual publication of glossy consultation documents relating to decisions which all those concerned know have already been taken. “The essence of consultation is the communication of a genuine invitation to give advice and a genuine receipt of that advice.” In our view consultation, to be effective, needs to take place early—while the consideration of possible options is taking place. If the proposals for the establishment of LINKs are to be effective we would like to see a situation where those involved in their local LINK are not surprised by the announcement of any proposal for substantial changes of service in their local area because they will have been involved at an early stage.

Martin Rathfelder
Socialist Health Association
10 January 2007

Evidence submitted by South East Coast Strategic Health Authority (PPI 112)

Key Points

1. The over riding purpose of Patient and Public Involvement is to improve the services which the NHS and other providers offer and so improve the:

   Experience that patients and carers have of these services. Patient and public involvement also serves to make the NHS more accountable and responsive to the communities it serves and people who pay for it.

   Patient and public involvement in various forms has been around since the 1970’s. The Health and Social Care Act 2001 has led to a greater effort and consistency of approach across the many organisations within the NHS. The latest reforms will strengthen and extend this to include social care, the regulatory bodies and external providers. Then also seek to broaden the independent scrutiny and monitoring of health and social organisations, so that staff more actively shape the development and delivery of services.

   Conclusion: Engagement and a better understanding of the NHS could extend into a wider public understanding of health and social care issues. This would encourage a more active citizenship, prepared to act on and take responsibility for improving their local communities as well as improving their own health and quality of life as individuals. Thus in the long term, people’s involvement and engagement with the
public sector can make services and the communities served more sustainable, based upon an increase in social capital and the better integration of people's needs with the services provided and a stronger ethos of partnership working to tackle together some of the long term health and socio economic problems.

2. Patient and Public involvement offers good value for money when its approach is proportionate to the desired outcome. It should operate across a number of levels from information, through participation to partnership, and should use a variety of tools and techniques based upon what works best for those patients, carers, staff and stakeholders you intend to engage with.

Having a range of voices taking part in planning patient and public involvement should ensure the delivery of good engagement processes.

Conclusion: NHS organisations need to ensure they invest the appropriate time, commitment, resources and drive to deliver good PPI throughout all the services they provide. This will lead to the desired cultural change, putting patients in a position to truly shape and influence service to improvements for themselves and other people.

3. As a minimum, Section 11 of the Health and Social Care Act 2001 places a duty on Primary Care and NHS Trusts and Strategic Health Authorities to make arrangements to involve and consult patients and the public:
   — not just when a major change is proposed, but in ongoing service planning;
   — not just in the consideration of a proposal, but from the outset in the development of that proposal; and
   — in decisions about general service delivery, not just major changes.

Recent changes to the Commissioning Framework have resulted in an additional duty to respond. Section 7 of the Health and Social Care Act 2001 gave powers to Local Authorities to establish Overview and Scrutiny Committees to:
   — take on the role of scrutiny of the NHS—not just for major changes but for the ongoing operation and planning of services;
   — refer contested service changes to the Secretary of State;
   — call NHS managers to give information about services and decisions;
   — report their recommendations locally; and
   — be consulted by the NHS where there are to be major changes to health services.

Section 11 requires that the NHS engage people in all circumstances when the NHS are changing and improving services, since this is a constant process of improvement for any public service. In the NHS as in other public services there are many and varied ways for patients, staff and the wider public to improve the way the NHS and other providers offer health and social care services.

Conclusion: Wider, formal consultation is guided by the findings of Health Overview and Scrutiny Committees (HOSC)’s and is dependent upon such terms as “substantial” and “significant” changes, which are difficult to define. Therefore, there is often a process of negotiation to clarify what should happen locally on a case by case basis and it is beholden on local NHS organisations to involve HOSC’s early in agreeing what should be taking place.

Question 1

The purpose of Patient and Public Involvement is to improve the patients’ experience of health and social care and to improve the services offered

1. Introduction

Members of the patient and publics who use NHS services have been involved in commenting on how services are delivered since the 70s. The original premise for this involvement was for Community Health Councils to monitor and review the National Health Service and to recommend improvements. Since the Kennedy report on the Bristol Inquiry and the Health and Social Care Act 2001 the move has been to ensure that each NHS organisation has a statutory duty to ensure patients, carers and staff are part of team improving the NHS and its services by engaging directly with them and listening to their views and ensuring they shape the improvement of services. This has led to a significant increase in the level of involvement and the consistency with which all NHS organisations listen to patients and the public, there are a variety of ways in which people are able to have an impact on improving services from talking to Patient Advice and Liaison Services to taking part in a review of services there are many more opportunities for patients and carers to influence the way services are delivered.

This paper describes the framework in place in the SE Coast that is to support the transformation of public patient and community engagement in the NHS from being an “add on” to being an integral part of business. Whilst the recent local government bill and changes in the commissioning framework strengthen the need for the wider public sector to work in a more integrated way with their citizens and service users.
to ensure more sustainable communities. The nature of Patient Public Involvement and evidence in this field, suggest that an evolutionary approach that builds consensus and engages participation, leading to sustainable action, is the most successful approach, enabling the local NHS to fulfil its responsibilities under section 7 and 11. The question we address is how will the proposed reforms add value?

2. Context

*The NHS Plan 2000* clearly established the Government’s intention that patients should be “at the heart of the NHS”. The Government sees patient and public involvement as central to service planning and provision and a major driver for service improvement.

The 2005–08 *NHS Improvement Plan* *Putting people at the heart of public services* set out the Government’s vision for an NHS that is modernised to meet people’s increasing ambitions and expectations for public services.

“An NHS which is fair to all of us and personal to each of us offering everyone the same access to, and the power to choose from, a wide range of services of high quality, based on clinical need, not the ability to pay.” (*The 2005–08 NHS Improvement Plan Putting people at the heart of public services*)

The guidance *Creating a patient-led NHS* extends the government’s ambitions towards changing “the whole system so there is more choice, more personalised care, real empowerment of people to improve their health—a fundamental change in the NHS relationship with patients and the public.”

The recent white paper: *Our Health, Our Care, Our Say* focuses on a strategic shift towards locating more services in local community settings and closer to people’s homes. It will also change the way services are offered in the community. During the consultation, people told the government they want a more personal service rather than a one size-fits-all approach—services that put them in control. So the NHS needs to provide care that is led by the individual, not led by the system or restricted by bureaucracy. And health and social care need to help people with the information and support they need to take control of their own health and well-being. And the recent local government bill ensures that both health and social care will contribute to a step change in empowering local people to shape local services and to meet local needs.

3. National Vision and Principles

3.1 Principles

Creating a patient-led NHS sets out core principles that underpin the shift in emphasis from the NHS providing services for the public to an NHS that works in partnership with patients, carers and the public to improve their health and wellbeing, together with the services that support this.
3.2 **Partnership between NHS and the Public**

The idea of partnership between the NHS and the public is not new. Much patient and public involvement is already being carried out through delivering and improving services and other activities within the NHS. Furthermore, some progress has been shown in the results of patient surveys and the evidence of service change based upon the views of staff, patients, and the wider public. There is a national PSA target for Patient Experience for 2005–08 which informs part of NHS Local Delivery Plans and service improvement, monitored through SHA’s by the DH Recovery Support Unit which states:

“Organisations should secure sustained national improvements in NHS patient experience by 2008, as measured by independently validated surveys ensuring that individuals are fully involved in decisions about their health care, including choice of provider.”

To be effective Patient and Public Involvement needs to be conducted on two levels:

— the individual level—involving patients in discussions and decisions concerning their own individual care and treatment; and

— the collective level—involving patients, carers and the wider public in broader considerations regarding the planning, provision and monitoring of services.

At both levels there is a continuum of involvement, (see question 2) which breaks down into three broad areas: Information, Feedback and Influence.

### Information

Information – where an organisation informs patients, carers and the public, to promote informed use of services and choice.

### Feedback

Feedback – where an organisation collects feedback from the patient experience, through qualitative and quantitative methods. The purpose here is to improve the quality of service delivery and the patient experience.

### Influence

Influence – where an organisation involves patients, carers and the public in policy and planning, or in decisions concerning resources, planning and reconfiguration. The purpose here is to improve the quality of decision making and promote accountability.

**Question:** Will LINKS provide a constructive sustainable compliment for involving local people?

**Question:** Will LINKS be able to reach those traditionally distanced by mainstream systems?

3.3 **Long term cultural change and service improvement**

The involvement of patients, users and the public has driven cultural change in the NHS over the last six years putting individuals and communities “on the inside” of the care system. NHS plans have deliberately emphasised that the service should not only be patient centred, focusing on need, but become a “Patient Led NHS” where patient and public views shape and inform policy and services so that the NHS is truly tailored to people’s requirements.

The aim is to ensure that the NHS and care services are transformed through better engagement with patients, users and the public by engaging local people, regularly seeking out and acting on their views and so creating responsive services that people perceive to be improving. The overwhelming and ongoing purpose of patient and public involvement or engagement is to improve the patient’s experience of health care. That tangible improvement to services and systems will be made as a result of peoples’ views, complaints, involvement in changing services, or choosing to volunteer or actively increase the range and support of services.

3.4 **Increased accountability and sustainability the “fully engaged scenario”**

With patients, partners and the public influencing change in the NHS there is an increased public accountability of the National Health Service. Fundamentally, citizens have a right to be involved in decisions which affect their lives whether as patients or carers or taxpayers, people should know about and be party to decisions which affect their health and wellbeing as individuals and as members of their communities. Research has shown that empowered patients who understand the services and the choices available to them make better informed decisions.
Derek Wanless in his papers for the treasury: *Securing our future health: taking a long-term view* (2002) and *Securing good health for the whole population* (September 2004), has clearly documented that one of the key means to achieve sustainability is a “fully engaged” population which is capable of taking greater responsibility for maintaining and improving their health and wellbeing, so that the finite resources of health and social care can be used effectively to support those who require additional assistance. This approach enables people to sustain an independence and quality of life with adequate public health and social care resources at our disposal. Rising patient and public expectations will place increasing demands on those providing healthcare, calling for continuous service improvements.

There is a wide spread recognition that the health system needs to become more people centred with the interests of the public, patients and customers given greater prominence and more influence in decision-making at all levels. This will create new opportunities for people to take an active part in managing their own health and become “expert patients” in managing their care with support from health professionals.

The Transforming Chronic Care Programme (TCCP) in Surrey and Sussex conducted a survey of almost 24,000 people with long term conditions or their carers which showed that: people generally felt they needed more information about their condition and their care, better access to services and more involvement in planning services and care. They said they felt health and social care services staff did not work in partnership and services were not integrated. The TCCP set up a service user group comprising over 100 members. Top of their agenda was to empower people with long-term conditions to express their needs more confidently when working with health professionals which they felt could improve their involvement in planning their care. Delegates at a meeting in September 2006 said they did not always find it easy to express themselves when talking to clinicians and that this prevented them from taking control of the management of their care, particularly in a large county where there is a two tier system and Local Strategic Partnerships in place. It will be interesting to see how LINKS can add value to these current planning processes.

3.4.1 360 Evaluation

The NHS is a national service which is continually striving to improve—its overall services, its staff, technology and techniques, and the overall patient pathway. This requires constant and ongoing evaluation of the services currently provided, identifying ways to improve and strengthen services and systems. The expertise of staff, patients, carers and clinicians is needed in order to make those improvements to systems and services. If the patient and public perspective was missing from this evaluation process, the learning would be limited and understanding incomplete.

Question 2

*What form of patient and public involvement is desirable, practical and offers good value for money?*

1. Introduction

There is no single solution to effective patient and public involvement. Best practice and experience show that a suite of methods is desirable if engagement is to be meaningful. Appropriate practical choices from that suite can be made to ensure good value for money. At the same time the programme of involvement should be systematic and consistent, supporting health communities to:

- Ensure high quality outcomes of value to users and communities.
- Transform services through continuous learning and improvement based on people’s (staff and stakeholders) feedback.
- Ensure improved services are responsive, accessible and accountable to local populations.

Being responsive to patients’ experiences as consumers of our care and listening to people in local communities is paramount to ensuring that where, when and how services are delivered is appropriate to local need. Without first capturing and being responsive to the needs and wishes of patients, users and carers, we will continue to experience poor use of resources and less effective care.
Continuum of involvement based upon the Arnstein ladder of participation

<table>
<thead>
<tr>
<th>Giving Information</th>
<th>Getting Information</th>
<th>Discussion</th>
<th>Participation</th>
<th>Partnership</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exhibitions</td>
<td>Phone Ins</td>
<td>Focus groups</td>
<td>Patient Stories</td>
<td>Community projects</td>
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<tr>
<td>Leaflets newsletters</td>
<td>Questionnaires</td>
<td>Target groups</td>
<td>Shadowing</td>
<td>Service change</td>
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<td>The media</td>
<td>Interviews</td>
<td>Public Meetings</td>
<td>Citizen juries</td>
<td>Citizen juries</td>
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<td>Staff</td>
<td>Feedback Forms</td>
<td>Seminars</td>
<td>Patient reps</td>
<td>Patient reps</td>
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<td>Postcards</td>
<td>Conferences</td>
<td>Health Panels</td>
<td>Health Panels</td>
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<td>Open days</td>
<td>Community</td>
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<td>Community plans</td>
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<td></td>
<td>Citizen Panels</td>
<td>voluntary networks</td>
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<td></td>
<td>Patient diaries</td>
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This continuum demonstrates the levels of engagement, from giving information through to the fully engaged level of “partnership”. Good engagement should be at a level proportionate to the expected outcome.

For example: a one-off focus group aimed at mapping patient information, which leads to the implementation of improved information, provided to patients in a timely fashion is a valued outcome. Equally, the involvement of patients and carers at the beginning of a cross sector service review which continues through to implementation of a consolidated specialist service in two centres of excellence is of value to the whole health community and several organisations. An example of service user engagement in the Renal and Vascular Review of services across Kent and Medway appears in Appendix 1.

Both these examples benefit and improve the patient experience, but they are each of a scale of time, resources and involvement applicable to the needs and outcomes.

Good patient and public involvement and engagement ensures patients and communities become more empowered, able to make choices as consumers about how, where and when they access and utilise services (or choose not to). Services need be customised to individual needs. At the core of the fully engaged scenario is the need for people to feel more confident in themselves and their future in order to take more responsibility for their health and make changes in their choice of lifestyle. It is also about enabling people with long-term illnesses or medical conditions to have a better quality of life.

In order for our stakeholders/patients to become fully engaged we must:

- Address problems that people have with finding appropriate information about their health.
- Ease difficulties people have in considering the wider social costs of particular behaviour.
- Address the inequalities that arise from socio-economic or differences and ingrained deprivation.

1.1 How can we do it?

Not only must people take action to manage/maintain their own health, but organisations such as the NHS, local authorities, businesses and voluntary and community sector organisations must also get involved in local partnerships. This will increase the social capital that a healthy active community can offer, not just in terms of improved health and social care but in the broader gain in communities which are actively trying to improve their quality of life and socio economic standing.

2. The Role of the Strategic Health Authority (SHA)

The role of the SHA is to ensure the local NHS organisations in its area fulfil their statutory responsibilities to ensure patients/users, carers and public are consulted and involved in the commissioning, development, planning and operation of services. The methods used may vary according to the type of organisation and the nature of their relationship with users. For example: Ambulance Trusts have a
naturally transitional relationship with many of the users and so rely upon PALS, and comments received via surveys or occasional focus groups/events; whereas Mental Health Trusts often have sustained relationships with service users over a number of years, resulting in the users increased ability to be involved in a variety of work at a number of levels of governance and engagement.

The SHA performance manages the organisations in its area and assesses their progress in the development of PPI, identifying areas of strength and areas which require further development. See Appendix 2.

The SHA is working with the organisations it supports to ensure they:

- Build infrastructures, systems and processes to develop robust and systematic involvement and engagement of a wide range of patients/users, carers, citizens and communities in all aspects of the organisation’s work.
- Involve the patients and the public in service planning, design, development, delivery, evaluation and improvement, commissioning and contract/quality monitoring governance, regulation and inspection, recruitment and selection.
- Develop appropriate proactive approaches to involving “hard to reach” groups with particular emphasis on equalities and tackling inequality to ensure organisations are responsive and accountable to all sections of the community.
- Develop and maintain an open, two-way, ongoing engagement with patients/users, citizens and communities to identify opportunities, challenges and options for change in particular when consulting and involving patient/users, citizens and the community from the outset of any reconfiguration or service change.
- Begin PPI from initial discussions not when proposals have been drawn up.
- Explain the need for change quickly and clearly, creating an honest dialogue about “trade-off’s” and the potential impact of patient/public chosen/preferred options on their health economy.
- Demonstrate active engagement in tackling discrimination, and reach out to work with differing parts of the community where it is suitable and comfortable to engage with them. Including the engagement of Patients fora, PPI Forums and community representation in the development of strategy and actions to tackle discrimination.
- Publish regular reports detailing what the organisation has done differently as a result of user/public views, explaining why some suggestions may not have been taken forward and responding to the varying needs of the communities served.

3. The Role of the PCT’s and Trusts is to

- Ensure access to and choice of appropriate services with high levels of support and information for patients to make choices.
- Encourage and support self care, and wellbeing for the population served.
- Support health literacy and on going proactive information and communication.
- Involve patients and public in defining service requirements (health and social care) for commissioning purposes including Practice Based Community (PBC).
- Monitor quality of provision (contract management) and ensure services are appropriately shaped, through an interface with providers, and with the involvement of patients/public.
- Meet national standards and National Service Frameworks

The Role of Foundation Trusts and other Trusts and providers is to

- Involve and empower patients.
- Reach out to and engage with local communities.
- Be accountable to local people through, for example, Membership of their Foundation Trust, governance structures etc.
- Ensure consideration of Overview and Scrutiny Committee (OSC’s), Local Strategic Partnerships (LSP’s), Local Authorities (LA’s) and Patient and Public Involvement Forums and potentially LINks (PPIF’s) etc.
- Meet Healthcare Commission standards.
- Ensure membership will need to explore potential interaction with LINks to engage wider communities.
4. Full Engagement in Service Improvement. In some Circumstances, the SHA, PCT’S and Providers Need to Work Together and Focus on Two Key PPI Actions

— Ensuring a range of appropriate and effective approaches is used to involve and engage patients, users, carers and the communities from all sections of the population particularly those from hard to reach communities and those with communication difficulties.

— Establishing a process for systematically collecting, analysing and acting upon patient and public views and ensuring this feedback directly influences and informs plans and activities.

4.1 Key Criteria

To ensure a patient-led approach, all stages of the work/planning should offer evidence to demonstrate that:

— Patients and the public have been involved in detailed discussions—what mechanisms have been used to actively engage users, patients, carers and the public?

— Health communities have listened to patients/users and the public and recorded their views in improvement plans and activities.

— Actions resulting from patient and public feedback have informed plans and activities eg from Patient Surveys, PALS, Complaints, Compliments, User and Patient Engagement Groups, Focus Groups/Workshops, PEXIS etc (most Trusts in Trent have Patient Experience Learning groups that routinely collate and action feedback of this type).

— The plan reflects patient, user and public input. Where there is no input health communities need to justify not including patient, user and public views.

— Diversity is reflected, acknowledging the wide range of community needs, interests and perspectives, particularly those from minority communities and those with special needs or communication difficulties who are harder to engage.

— Expected benefits and outcomes that patients, users and the public should see as a result of the plan. ie an explanation of how plans will make a difference to, and improve services, health and well-being, and experiences for patients, users, carers and the public.

— Plans are “patient/user-centred” and grounded in the patient/user perspective on an ongoing basis eg patient and public involvement in monitoring and evaluation.

4.2 Plans should also evidence appropriate working in partnership with

— Local Authorities particularly Social Services.

— Local Strategic Partnerships.

— Local Authority Overview and Scrutiny Committees (OSC’s).

— Patient and Public Involvement Forums.

— User, carer and citizen groups and voluntary sector organisations.

5. Effective and Meaningful Involvement

It is important to build upon existing relationships with patients, users, carers and the public, utilising groups and processes already in place within health communities rather than creating new mechanisms or activity.

Legislative policy and practice emphasise the “independent” structures: Overview and Scrutiny Committee (OSCs), Patients Advice and Liaison Services (PALS), Independent Complaints Advocacy Services (ICAS), Patient and Public Involvement (PPI) Forums and more recently Local Involvement Networks (LINks) which will formalise the existing relationships what the select committee should consider is how these can continue to add value to patient and public involvement within the NHS whilst retaining their independence. This has been a strength of the Patient and Public Involvement Forums who have mirrored the NHS structures and in the SE Coast area, had a productive relationship with the NHS organisations acting as critical friends able to work with us as well as independently.

5.1 The approach

Under current Section 11 practice from Strengthening accountability all organisations should have in place robust PPI infrastructure, systems, methodology, and monitoring, this should include:

— PPI Operational Lead, Executive Lead and Board level PPI “champion”.

— Ongoing PPI monitoring and evaluation of activity.
— PPI integrated into commissioning processes.
— PPI Policy/Strategy and Implementation Plan.
— Clear lines of accountability for PPI and strategic fit with organisational decision-making structure.
— PPI integrated into HR processes including induction, staff appraisal/KSF and objective setting, recruitment and selection.
— Ongoing PPI Staff and Board level workforce and leadership development programme.
— PPI impact assessment included in all Board papers relating to service change and improvement to meet Section 11 requirements.
— A range of approaches for engaging patients and the public across diverse communities.
— Clear mechanisms for organisational learning from user/public feedback—“Patient Experience Learning Groups”.
— Mechanisms for feedback and responding to patients and the public.
— Annual PPI Report.
— Active and well resourced PALS service.
— Impact on changes to access to services for those most in need.
— User Expenses Policy and ring fenced resources.
— Good Practice Guidelines for PPI.
— Use/Public Engagement Steering Group.

5.2 Currently each NHS organisation has a Patient Advice and Liaison Service (PALS)
— PALS has an important role in organisations to:
  — deliver and maintain a customer care/education/support function at the user/public interface;
  — Provide valuable organisational intelligence on user/“customer”/public experiences, preferences and needs to inform:
    — commissioning;
    — continuous service improvement; and
    — understanding market share/market management.

PCT’s need to ensure that any new arrangements for services meet national guidelines on complaints and PALS
Organisations need to strengthen and develop the capacity of the PALS service ensuring the DH PALS Core Standards are met:
— PALS service is identifiable and accessible to the community served by the Trust/provider.
— PALS is seamless across health and social care.
— PALS is sensitive and provides a confidential service that meets individual needs.
— PALS has systems that make their findings known as part of routine monitoring in order to facilitate change.
— PALS enables people to access information about health and social care services/provisions and issues.
— PALS plays a key role in bringing about culture change in the NHS and social care, placing patients at the heart of service planning and delivery.
— PALS will actively seek the views of service users, carers and the public to ensure effective services.
See Appendix PALS in focus.*

6. The Future of Public Engagement
Recent guidance and policy has sought to create a system capable of delivering this vision and supporting the engagement of the Third sector to have a stronger voice in commissioning, needs assessment, policy development and delivery looking at the Third Sector Commissioning Task Force and the Stronger Local Voice policy recommendations aiming to:
— Build the capacity of the Third Sector to realise its full potential in the health and social care system and to benefit from greater plurality in Commissioning.

* Not printed here.
— Promote understanding among Commissioners of the Third Sector’s contribution to strategic planning, needs assessment, health improvement, reducing health inequalities, (specifically equality, diversity and social inclusion related), service delivery and community and individual capacity building/empowerment.

— Collate and share effective practice in partnership work between statutory agencies and the Third Sector within the region including Local Strategic Partnerships, Local Authorities and social care.

— Facilitate and support systems reform, which builds on this learning.

The newly published Local Government and Public Involvement in Health Bill which details the reform of the current arrangements for patient and public involvement in the provision of health and social care services has also contributed to a significant step change in the empowerment of citizens and greater engagement of local people in shaping public policies and services. Better joint working should provide the benefits of:

— Empowered citizens with an individual and collective responsibility for health.

— A better understanding of the health needs of “marginalised” groups.

— More responsive and inclusive services, leading to equality of provision, adherence to Compact principles.

— Greater choice for service users.

— Sustainable Third sector provision.

— Opportunities for joint commissioning optimised.

A strengthened leadership role for local authorities to bring local services closer to communities, making them better coordinated and offering better value for money. Local Area Agreements (LAAs) and the accompanying duty to cooperate should further incentivise local agencies to work with their communities in a joined up way to improve services and the quality of life and work together to reduce long standing problems such as health inequalities.

A new duty will require local authorities to inform, consult and involve local people in running local services; and councillors will be empowered to resolve issues of concern to the communities they represent (if necessary by requiring consideration by Overview and Scrutiny Committees).

There will be significant social capital from the expected rise in engagement and empowerment of citizens and communities by local government. This should benefit service delivery and improved partnership working at the local level based upon local needs, plans and implementation.

The Community Call for Action and the Overview and Scrutiny and governance reforms will provide additional mechanisms to enable a person or persons to require their local authority to consider an issue which is causing concern to the community. See Citizens Involved: Community Participation in Neighbourhood Renewal (2004) For evidence of how engagement can improve trust see ODPM, New Deal for Communities 2001–2005: An interim evaluation. Research Report 17, (2005).

Patient and Public Forums will be replaced by the introduction of local involvement community networks (LINKs) which will be at the heart of the new arrangements to strengthen the voice of local people. Each authority with social services responsibilities will be appropriately funded to carry out a new statutory duty to make arrangements providing for the establishment of a LINK in its area. LINKs are expected to build on the best of the work of the patient forums, creating a strengthened system of user involvement, which expands the opportunity for engagement.

— But will one size LINK suit all? Most communities have several constituent parts who may not work well together, and where large sectors may dominate.

— Will LINKs be able to ensure a community led “health impact assessment” process?

In summary, the new policies and guidance should give local people more influence over the services and decisions that affect their communities; provide effective and accountable strategic leadership; operate in a performance framework—for local authorities working alone or in partnership—which supports citizen empowerment and secures better outcomes for all; and leads local partnerships to provide better services for citizens. Moreover, measures will facilitate improved engagement and empowerment of users and communities and more responsive and efficient local services.

This will bring a focus on:

— New relationships, systems, access routes and utilisation.

— New providers eg Voluntary Sector.

— The need for Identification and targeting-key of groups of potential patients.

— The need for organisations to understand their “market share”.

— Engaging target groups of future patients by “market segment” eg high risk groups, young people, mental health, older people etc.
— Engaging with future patients through:
  — Community outreach.
  — Alliances with retail and other sectors.
  — IT based solutions.
  — “Well Person Plans”.
  — Creative use of media eg Digital TV, Text messaging.
  — Engaging the public in non-NHS environments eg supermarkets, libraries etc.
  — Links to and feedback from Local Strategic Partnerships, Voluntary and Community Sector Organisations and Local Authorities.
  — Learning from public feedback.

Circumstances in which wider public consultation (including under section 11 of the Health and Social Care Act 2001) should be carried out and the form it should take

1. Creating an NHS Fit for the Future

Like many Strategic Health Authorities across the country, NHS South East Coast together with the local health communities in Surrey and Sussex, is taking a fundamental look at how and where NHS services are provided in the area. This programme of service review for the NHS across Surrey and Sussex, (and, subsequently Kent and Medway) has been called Creating an NHS Fit for the Future and is expected to result in far-reaching proposals for change. The programme is reviewing the way services are provided in light of people’s changing health needs in the 21st century to ensure that services: clinically sound, accessible and sustainable for the foreseeable future.

2. Purpose

To ensure a locally owned and driven review of services, that is supported by local people both within and outside of the NHS. The Fit for the Future engagement work is attempting to address an inherently complex challenge through a complementary set of interventions:

Stakeholder discussions: Introducing as wide a range of key players as possible into the discourse and its substantive challenges.
Deliberative Events: Enabling local citizens to appreciate and get to grips with the “trade-offs”. (For further information see appendix 3.)

Co-Design: Facilitating leading “players” (patients/public; clinicians; managers) to review and test the evidence for change and move towards collaborative problem-solving: improvement through informed engagement.

This is underpinned by ongoing Section 11 work by local health communities and is complemented by the ongoing communications, media, and public relations work, especially with local politicians, partner organisations and local campaigners.

3. Approach

The SHA has supported the local health communities through various planning programmes to ensure that there are active engagement strategies in operation by the PCTs and trusts throughout. These strategies and action plans offered stakeholders and the wider public a variety of opportunities to become involved in discussions around the drivers for change and their impact, the actual design of service change, and the subsequent proposals for service options in a formal consultation process.

Where large scale change to key local services for the general population is proposed, then there must be full public consultation, preceded by a lengthy period of discussion, awareness raising and involvement with local stakeholders which will support the development of plans for change and eventual consultation on options.

Through Fit for the Future we have learned that this is the only way to build an understanding of the reasons for change among stakeholders, and therefore, to engage people properly in a constructive debate about the options with shared responsibility. For details of the processes undertaken see appendix 3.

4. Developing an Understanding Leading to a more Informed View and a Shift in the Public’s Perception

Public engagement has been fundamental to each stage of the Fit for the Future programme. Through engagement, it is possible to ensure that any proposed changes to health services will be responsive to the concerns and aspirations of patients, carers and the general public. Throughout the programme, participants have been asked to comment upon and help improve the communication and engagement process itself. Aware of it’s the challenging aspects of the debate and the tensions of competing priorities; we consistently endeavour to improve the engagement process itself so as to improve the overall outcome.
Figure 1

PROCESS ARCHITECTURE: ENGAGEMENT IN CONTEXT (PROF BOB SANG)

TOP-LEVEL CONTENT
- Systems' Reform
- Financial Recovery
- Services' Reform

SHA STRATEGIC PLAN:
Service & Business Models
(including Turnaround)

TOP-LEVEL PROCESS

LOCAL HEALTH COMMUNITY PLANS
- Ambulance Trusts
- Partnership Trusts

ACHIEVING SUSTAINABILITY

SERVICE PRIORITIES & RECONFIGURATION

CLINICAL/STAFF ENGAGEMENT

INITIAL ENGAGEMENT
(May/June 06)

OPEN SYSTEMS ENGAGEMENT
(June 06)

EVIDENCE-BASED DELIBERATION
(Sept 06)

CLOSURE & HANDOVER
(Nov-Dec 06)

IMPLEMENTATION PLANNING
(Clinical/Staff Engagement)

TOP-LEVEL CRITERIA & RANGE OF OPTIONS

ARTICULATING POTENTIAL OPTIONS/SOLUTIONS

CLARIFYING PARAMETERS OF CHANGE

VISION & VALUES

WHOLE SYSTEMS DELIBERATION
TRANSPARENCY, INCLUSIVITY, CONTESTABILITY
(Test against Business & Outcomes Criteria)

STAKEHOLDER & 'FORCE FIELD' ANALYSES

ADDRESSING & NEGOTIATING EXPECTATIONS

RAISING AWARENESS

DEVELOPING UNDERSTANDING/ MEANING

IDENTIFYING QUESTIONS/ ISSUES/ SENSITIVITIES

OUTPUT 1

OUTPUT 2

OUTPUT 3

OUTPUT 4

Leadership Community Takes Forward

Development of formal proposals

Patient & Public Engagement

Leadership Community Engagement

PPIH Legislation & Guidance
5. Communication and Engagement

Through the development of thorough communications and engagement processes, the public’s awareness of changes to service provision is increasing as more detailed information will be on hand, outlining what services are available. “Providing patients with more information will help increase their confidence in the system.” (Member of public at deliberative event) An independent report of several events stated: “The general public need educating about which services they need and what is available to them, people need to know which service to go to for different kinds of treatment. Participants in both the deliberative events acknowledged that the media coverage of these changes so far has been very negative and we felt that (although we were not sure how) this needs to change. If these changes are going to be effective then they do rely on the public fully understanding them.”

Feedback from people in Surrey and Sussex includes the following quotes and views expressed at some of the deliberative events:

“Be careful to prepare the ground with local providers before moving services from hospitals to other hospitals or to the local GP service.”

“There is a need to consult local representatives, medical and non-medical.”

“Ensure the public has the full particulars.”

“Widen the scope of public consultation and ensure that it is perceived as being listened to, rather than a window dressing exercise.”

“Make it as simple as possible, publicise it as fully as possible.”

“Ensure the public are given full facts as well as the scenarios for change. It’s hard to debate something that is undecided. Be very careful that you are not accused of “spinning” to reach the scenario that suits your agenda.”

“Acute care and emergency care are not the only priority. The money is to be taken into account but patient priority is to get the best care. We need clear information not PR talk.”

“Allow for full consultation with all affected user groups before any changes are implemented.”

“Communicate the fact that this is a change in the strategy of delivering care (an improvement) and not a reduction in care; if this is indeed the case!”

6. Consultation

All of the Fit for the Future work so far has been undertaken prior to the formal consultation process which is due to start this spring. This early work provides a firm basis for wider understanding despite the negative media and public campaigns. It is clear that people can appreciate that tough decisions need to be taken to ensure health services are safe, viable and affordable, freeing NHS time and resources to improve health prevention and health promotion and meet the ambitions of the white paper Our Health Our Care Our Say for a broader range of services based within the community and offered closer to people’s homes.
“Co-Design”, “Deliberation”, “Stakeholder Engagement” are all means of enabling local people and frontline staff to consider the reasons for reform in a safe space that allows fear and aspiration to be acknowledged and heard. In order to do this there are seven highly contingent sets of data variables to be addressed—and each is dynamic and contentious:

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<thead>
<tr>
<th>Rhetorical</th>
<th>Reflecting policy and the Reform programme and political interests</th>
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<tbody>
<tr>
<td>Strategic</td>
<td>The “drivers” of change and their implications</td>
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<tr>
<td>Operational</td>
<td>The population ad service data</td>
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<tr>
<td>Financial</td>
<td>Historic and projected</td>
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<tr>
<td>Infrastructure</td>
<td>The estate ad related systems/resources</td>
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<tr>
<td>Local-Contextual</td>
<td>Critical additional factors: eg, transport, inequalities</td>
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<tr>
<td>And, crucially</td>
<td></td>
</tr>
<tr>
<td>Technical-Clinical</td>
<td>The evidence-base for safe and sustainable practice</td>
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</table>

Thus the assessment of the “trade-offs” between Clinical Safety, Accessibility, and Affordability that now forms the substance of most of the engagement work, will rely on the quality, contestability, and relevance (including meaning to diverse audiences) of the data used in the above process to affect a shift in “critical mass” of understanding.

7. The Challenges Faced and Lessons Learned So Far From Creating an NHS Fit For The Future are

7.1 Key Challenges

Early Involvement vs “Vagueness”

Whilst there are immense benefits to early engagement of stakeholders, including patients and the public in the development of proposals for change, this does create a period of uncertainty. Early involvement means engaging people in a discussion about the need for change and the challenges faced before there are plans or options on the table. However, this leads to a perception of the NHS being vague or worse withholding plans for discussion, and creating a vacuum filled by rumours which can fuel campaigns and media coverage ie a lack of understanding of what section 11 aims to achieve in terms of shared responsibility for designing new models of care whereas the reality was that the plans were slow to be finalised.

Stakeholder vs “Public Discussion”

Early discussion focussed on stakeholders and representatives of patients and the public eg Patient and Public Involvement Forums, Health Overview and Scrutiny Committees, Voluntary and Community Sector. However, especially once media coverage creates anxiety about future plans for hospital services, there is an expectation from the public that effectively a “full public consultation” will be running throughout the period of discussion—it would be impossible to resource or maintain this degree of public involvement for a year or more. (See A1ppendix 4 for full scale of work undertaken prior to consultation)

Balancing the messages

There is a complex balance between clinical safety and standards, patient needs and accessibility and affordability. It is extremely difficult to ensure these messages are heard and understood particularly in a challenged financial climate, any change is viewed as financially driven.

Clinical Leadership

Clinical leadership is absolutely key to the engagement process, as stakeholders and the public have a high degree of trust in clinicians. However, a hostile reaction to proposals for change makes it very challenging for clinicians to provide public support, particularly if colleagues are not supportive.

Aligning discussion with development of proposals for change

It is challenging to create a staged engagement process where the views expressed are constantly feeding into the development of plans for change in a meaningful way. The planning and engagement processes often run parallel with different pieces of work feeding into one another. Also the complexity of data can be a considerable challenge both in terms of language and density.
Involvement vs Reputation

There is pressure on the NHS to, on the one hand, be very open about challenges and reasons why services need to change, and, on the other, to minimise negative coverage and maintain a positive public reputation. This can create tensions in terms of managing an effective engagement process.

Feedback loop

There is need for a constant feedback through various modes to those involved in the planning process to feedback what has been said, and how it will be incorporated into the plans. (see Appendix 5)

7.2 Lessons Learnt

— There must be an active engagement of key players and a constant liaison, ensuring that critics and campaigners are invited to work with the NHS and share responsibility for addressing the challenges public services face.
— A lot of time needs to be invested with stakeholders to develop understanding — this is time well spent, but it is impossible to do this with the whole of the general public. Deliberative events give a far more informed view than traditional public meetings, but the public prefer the public meetings! And those monitoring process may expect them?
— Close working with Health Overview and Select Committees from the earliest stage means greater clarity and congruence.
— Ensure clear and well communicated processes throughout so that people understand the different stages and the reasons for involvement before plans have been developed.
— Clarity of messages about change — should be simple, open and direct.
— Openness and transparency is fundamental.
— Identifying clinical spokes people and supporting them to present clinical issues and drivers for change to the public and stakeholders.
— Analysing and responding to concerns — create a constant feedback loop to demonstrate listening and the value of people’s involvement. Also enables adjustment of the approach to involvement to meet needs and expectations.

8. What are the circumstances in which consultation may not be required?

Where full scale public consultation seems inappropriate but is currently sometimes expected, is in terms of the closure or relocation of small numbers of beds or of a specialist service. Small numbers of bed closures are often a part of the NHS adapting to changing needs and practices and whilst there should be discussion with key stakeholders around the reasons for such adjustments, full scale public consultation on such issues does not usually seem the best use of resources, or conducive to the NHS operating most effectively. Any engagement should be conducted as part of the requirements under section 11 guidance rather than full and formal consultation under section 7 guidelines.

There are also difficulties where a change is proposed for very strong clinical safety reasons. Consultation then turns into a communications/information exercise where the public may rightly feel the decision is already made — because circumstances are calling for urgent action.

This kind of situation can then damage genuine engagement and consultation processes where there is a real choice to be made and flexibility about the way forward which patients’, partners and the wider public can influence. Maybe there should be a different name for an “informing” type “consultation” where urgent changes need to be made to differentiate from more interactive processes where there is mutuality in finding potential solutions.

Candy Morris
Chief Executive, South East Coast Strategic Health Authority
10 January 2007
APPENDIX 1
CASE STUDY—RENAL AND VASCULAR REVIEW

4. PATIENT AND PUBLIC INVOLVEMENT (PPI)

This process involved a structured method of seeking patients/public/carers views. The process adopted was to visit and contact consultants and specialist nurses who agreed to contact their patients, who gave their consent to pass on their contact details. They were then personally invited to join small discussion groups.

Discussion groups were set up in four locations—Maidstone, Canterbury, Medway and Ashford. A total of 40 patients/carers attended these groups. An independent facilitator, engaged from the college of Health led these discussion groups. The purpose of these groups was to:

— Ask people what service they use.
— What it is like to be a patient?
— What is their experience of services in Kent and Medway?
— What is important to them in receiving a service?
— What are the important aspects of receiving a good service?

The emerging themes from these discussion groups were:

— Waiting times for transport.
— Quicker and more accurate diagnosis.
— Reviewing times for outpatient appointments, eg late pm.
— Specialist nurses and outpatient clinics.
— Peer support patients “buddy” system.
— Dedicated central renal centre, including specialist nurses in OPD.
— More detailed information when first diagnosed in understandable language.
— Need for service in county before and after transplant surgery.
— Inadequate patient support services.

Developing an expert PPI group

Volunteers were requested from these groups who would be involved in further re-design of services. They are experts from the point that they are experiencing first hand what it is like to live with chronic disease, eg renal failure. This personal experience makes them experts. They are prepared to share this experience to convey knowledge about living with this condition or illness to others and be involved in developing PPI in this particular review.

Patient expenses

A policy and process has been established to reimburse patients/carers for travel expenses when attending discussion/involvement sessions and the agreement of a one-off additional reimbursement payment for specific work—eg presentations at conferences etc.

Working conference

“Making it Happen” working conference on 19 May 2003 at the Hilton Hotel, Maidstone, was organised and attended by 95 stakeholders. The purpose of this conference was to:

— Bring together work from three of the review sub groups, namely commissioners, Clinicians and patient/public/carers.
— To share the achievements to date by identifying opportunities for redesign and approving these specialist services.
— To hear the views and experiences of patients/carers who use these services.

The outcome of the conference helped clarify and produce the basis for future proposals for wider public consultation and scrutiny across the county’s diverse community. The delegates who attended the conference represented:

— Two thirds NHS and local Authority Managers, NHS Clinicians and front line staff.
— One third patients/carers/public representatives.
Overview and Scrutiny Committee (OSC) Involvement

The Health and Social Care Act 2001 makes statutory provision for local authorities with social services responsibilities to extend their scrutiny and overview functions to cover the NHS. The aims of the NHS overview and scrutiny are:

— The focus is on health improvement, bringing together the responsibility of local authorities to promote the social, environmental and economic well-being and the power to scrutinise local services provided and commissioned by the NHS.

— To address issues of health inequalities between different groups and working with NHS and other partners to develop a dialogue to achieve health improvement.

— NHS bodies have a duty to consult the local OSC on any proposals under consideration for any substantial development of the health service in the area.

Two meetings were held with Kent County Council (KCC) and Medway OSC officers. The purpose of these were:

— To inform those present of the process of the review.

— To inform and understand the process and engagement of the OSC in both Kent and Medway.

— To share the consultation document and process.

5. Consultation Document

This reflected the discussions from the full range of stakeholders involved in this review. It identified and sought views on the key factors which had been established as contributing to what is considered to be best practice in providing a specialist service. These factors will decide the criteria which will be used to help PCTs and PPI assess the options of service models and arrive at a decision for future development and implementation.

Stakeholders and patient/public/carers representatives were involved in writing and agreeing the context and content of the consultation document. This involvement included conference presentations, input from the discussion group sessions and a half day workshop on 9 June when 18 individuals attended to scrutinize and adjust the draft document. Those 18 attending represented one third NHS staff and two thirds patient/public representatives.

Finally, the consultation document was signed off by the Review Project Team and four patient/public representatives after further input and comments had been received from steering Group members.

6. Subsequently those patients and carers involved in the review have been part of the implementation team and were recently present at the opening of the Medway Centre of excellence. They were thoroughly heartened to see other patients receive the treatment they require within the best facilities and with a responsive service which they had helped set up.

APPENDIX 2

SURREY & SUSSEX SELF-ASSESSMENT FRAMEWORK FOR PATIENT & PUBLIC INVOLVEMENT (PPI)

Introduction

This self-assessment framework aims to draw together the expectations, requirements and good practice around PPI into one place. By self-assessing against this framework, organisations will be able to:

— Assess progress in developing PPI—identifying areas of strength and areas which require further development.

— Identify risks in not meeting key requirements such as the Section 11 duty to involve and consult.

— Compare progress with other organisations and identify sources of good practice elsewhere.

— Provide evidence to inform the organisation’s declaration against the health & social care standards, to inform the Strategic Health Authority (and if appropriate the Department of Health), and to inform independent scrutiny organisations such as Patient Forums and Overview & Scrutiny Committees.

Key Audiences

— The Board.

— The lead executive & non-executive directors.

— The PPI, clinical governance or other group overseeing PPI within the organisation.

— Operational lead(s) for PPI.
This framework is based on key guidance documents and national frameworks (listed below), and has drawn on frameworks used in other Strategic Health Authorities. Its development has been overseen by a small working group of PPI operational leads from NHS organisations (who also piloted it), and has input from the wider network of PPI leads and other audiences.

**Key Documents**
- Strengthening Accountability—Policy and Practice Guidance.
- National Standards, Local Action—The new health and social care standards.
- Choice, Responsiveness and Equity.
- PALS National Core Standards.
- NATPaCT Competency Framework, Section 7—Community Patient and Public Involvement.
- Performance Improvement Framework for PPI (SHA PPI leads/DH, 2003).

**How to Use this Framework**

This is a self-assessment framework and there will therefore inevitably be an element of subjectivity. It is helpful for the self-assessment to be undertaken by a small group (e.g., operational lead, PPI Forum representative, lead NED, lead Director, staff member) to bring different perspectives and to form a consensus. It will certainly be necessary to consult with colleagues when completing certain parts of the self-assessment. It is important to be as honest as possible in order to get the maximum benefit out of using the framework.

**The Framework Structure**

The framework is made up of 24 competencies, within which there are a series of objectives and actions which contribute to achieving that competency. There is a line to complete for each action as follows:

<table>
<thead>
<tr>
<th>Objective</th>
<th>Action</th>
<th>Position statement</th>
<th>Evidence</th>
<th>Red</th>
<th>Amber</th>
<th>Green</th>
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<tbody>
<tr>
<td>1</td>
<td>Statement describing an overall objective</td>
<td>1.1 A specific action which contributes to achieving the objective and competency</td>
<td>Your brief statement of where you are against this action. Eg fully achieved, requires xx to complete, not achieved—plan in place etc</td>
<td>Evidence which supports your position statement eg reference to an action plan, a system, process or policy.</td>
<td>A final rating</td>
<td></td>
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*(Xx)* Cross references against the relevant criteria for assessing the Healthcare Commission core standards in The annual health check. Where appropriate the developmental standard is also identified in this way. The primary core standard for PPI is C17 and cuts across the entire framework, so has not been identified separately.

The final rating of red, amber, green should take into account the position statement and the evidence—an action cannot be green if there is no evidence to support this. Definitions of red, amber and green are:

- Red—Not achieved and limited progress made
- Green—Fully achieved with supporting evidence
- Amber—Not fully achieved, but good progress being made
COMPLETION DETAILS

Lead responsible for completion: Name: ____________________________ Role: ____________________________

Others involved in carrying out the assessment:

1. Name ____________________________ Role: ____________________________

2. Name ____________________________ Role: ____________________________

3. Name ____________________________ Role: ____________________________

4. Name ____________________________ Role: ____________________________

5. Name ____________________________ Role: ____________________________

How was the assessment carried out?

How has the assessment been communicated (who has it been shared with and how?)

Section A: Patient & Public Involvement Strategy & Action Plan

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<tr>
<th>Objective</th>
<th>Action</th>
<th>Position statement</th>
<th>Evidence</th>
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<tbody>
<tr>
<td>A1</td>
<td>Carry out a baseline assessment of PPI activity across the organisation (ref: strengthening acc)</td>
<td>1.1 A comprehensive baseline assessment has been carried out, identifying strengths, weaknesses and development needs.</td>
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<tr>
<td>A2</td>
<td>Develop a clear PPI strategy and action plan, agreed by the Board (ref: strengthening acc)</td>
<td>2.1 A PPI strategy and action plan have been produced with the involvement of key stakeholders and has been agreed by the Board.</td>
<td>2.2 A reporting mechanism is in place to monitor progress against the action plan.</td>
<td>2.3 The PPI strategy demonstrates links to the local planning and policy process (incl LDP) and there is evidence that patients and the public are involved in the organisations internal planning processes.</td>
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<tr>
<td>A3</td>
<td>Develop an infrastructure to support the PPI strategy</td>
<td>3.1 There are designated NED, executive director and operational leads for PPI.</td>
<td>3.2 There is a designated group or committee that oversees PPI strategy and activity within the organisation.</td>
<td>3.3 Progress in achieving PPI is evaluated annually and reported internally and externally.</td>
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</table>
### Section B: Supporting Patient & Public Involvement Activity & Integration

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<th>Action</th>
<th>Position statement</th>
<th>Evidence</th>
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<tbody>
<tr>
<td><strong>B1</strong> Support staff to undertake PPI activity</td>
<td>1.1 PPI is included in staff job descriptions and appraisal processes.</td>
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<td>1.2 PPI is included in staff induction. Advice and training are available to support staff on PPI.</td>
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<td>1.3 Examples of good practice are shared across the organisation</td>
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<td><strong>B2</strong> Support patient, public and voluntary sector representatives to participate in PPI activity</td>
<td>2.1 There is clear information for patients and public on opportunities to get involved in improving services.</td>
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<td></td>
<td>2.2 Patient/public representatives are offered training and support to help them participate fully.</td>
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<td>2.3 There is an agreed policy on reimbursement of expenses that clarifies terms of payment for time if appropriate.</td>
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<td></td>
<td>2.4 A wide range of methods are used to involve patients and public.</td>
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<td></td>
<td>2.5 There are specific measures to involve harder to reach groups.</td>
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<td><strong>B3</strong> Learn from good practice and experience elsewhere</td>
<td>3.1 Staff involved in PPI, PALS and related areas participate in local and SHA wide networks.</td>
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### Section C: Systems for Patient Feedback

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<th>Position statement</th>
<th>Evidence</th>
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<tbody>
<tr>
<td><strong>C1</strong> Improve the 5 key dimensions of the patient experience through; learning from patient survey results developing action plans, acting on any concerns to improve service delivery and the patient experience.</td>
<td>1.1 A patient survey is carried out annually and the results of the survey are made public and shared with staff and PPI forum.</td>
<td>*(C14c) *(D8)</td>
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<td>1.2 Areas previously identified for action have shown improvements.</td>
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<td></td>
<td>1.3 An action plan is produced with involvement of staff and stakeholders and has been shared with Board, who also monitor progress.</td>
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<tr>
<td><strong>C2</strong> Provide an accessible PALS service which can resolve patients’ questions and problems, provide information and receive feedback (ref national core standards)</td>
<td>2.1 A fully operational PALS is in place, accessible and publicised across the community.</td>
<td>*(C13b) *(C14a)</td>
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<td>2.2 The PALS has been assessed against the national standards.</td>
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<td>2.3 There is a development plan for PALS based on the national standards.</td>
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<td>2.4 Staff are aware and trained in the role of PALS and their own role in overall PALS approach.</td>
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<td><strong>C3</strong> Provide a well-publicised, non-discriminatory complaints process.</td>
<td>3.1 There is a process for formal complaints and information is available to the public/patients.</td>
<td>*(C14b) *(C14a)</td>
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</table>
## Section D: Partnership Working

<table>
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<th>Position statement</th>
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</table>
| **D1** Demonstrate a strategic approach to planning, PPI and policy through partnership working | 1.1 | There is evidence of strong partnership working with local authorities, voluntary and community sector and other NHS through LSPs, local compacts and networks to develop patient/carer involvement.  
1.2 | The organisation has been involved in the development of, and has signed up to its local compact(s). | *(C6)* | | |
| **D2** Demonstrate positive working relationships with independent PPI structures | 2.1 | There are agreed working arrangements with PPI Forum(s) and evidence of a good working relationship  
2.2 | Liaison arrangements have been agreed with HOSC(s) and evidence of a good working relationship.  
2.3 | There are procedures in place to consult with HOSCs on any proposal for potentially significant service variation. There is evidence of consultation with HOSCs. | | | |
| **D3** Promote recognition of and support for carers needs, and make arrangements to involve carers. | 3.1 | There are links with carers groups and networks. Carers are supported to be involved in all aspects of PPI.  
3.2 | The organisation contributes to a local carers strategy. | | | |

## Section E: Patient Information

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<th>Objective</th>
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<th>Position statement</th>
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</thead>
</table>
| **E1** Provide a range of information to patients to support choice and self-care (ref info for choice and info leaflet guidance on DH website) | 1.1 | There is evidence of a range of information in place, including what to expect during treatment, aftercare, and from services and health promotion.  
1.2 | There are protocols in place for style, content, format and distribution.  
1.3 | Information is made available to support choice.  
1.4 | Information is available to support self-care and prevention.  
1.5 | Information is available in a range of formats and languages.  
1.6 | Patients/public and staff are involved in producing and reviewing information | *(D9a)* *(D9b)* *(C16)* | | | | | |
<table>
<thead>
<tr>
<th>Objective</th>
<th>Action</th>
<th>Position statement</th>
<th>Evidence</th>
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<tbody>
<tr>
<td>E2 Provide patients with a copy of letters sent between clinicians about their individual care (ref copying letters to patients info, guidance and toolkit)</td>
<td>2.1 A policy for “copying letters to patients” has been produced and agreed. 2.2 There is an action plan for implementing the policy and progress/compliance is monitored. 2.3 The organisation is compliant with the policy.</td>
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<tr>
<td>E3 PPI links closely with communications strategy</td>
<td>3.1 The organisation has a proactive communications strategy with links to PPI. 3.2 Interpreting services are available to all patients.</td>
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**Section F: Ensuring PPI has an impact**

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<th>Action</th>
<th>Position statement</th>
<th>Evidence</th>
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<tbody>
<tr>
<td>F1 Ensure patient feedback influences service planning and development</td>
<td>1.1 There is evidence that issues and trends identified from PALS, complaints and other sources of feedback have consistently been acted on. 1.2 There is evidence of action taken as a result of patient survey findings and that the survey findings have improved the patient experience and influenced PPI activity. 1.3 There is evidence of the organisation responding to reviews from PPIFs, HOSCs and other groups. *(D8) *(C14c)</td>
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<tr>
<td>F2 Ensure that the adequacy of PPI is challenged and assured at Board level</td>
<td>2.1 All Board members are familiar with the key PPI requirements and are equipped with the right questions to ask. 2.2 There is a section on Board papers which details how PPI has informed the decision.</td>
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<td>F3 Measure performance from a patient/carer perspective *(D8) *(C14c)</td>
<td>3.1 Data collected about patient/carer experience is used to inform service planning and delivery.</td>
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<td>F4 Ensure staff can action patient feedback</td>
<td>4.1 Staff have clear routes for communicating patient feedback and know what happens as a result.</td>
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**Section G: PCT—specific section**

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<th>Position statement</th>
<th>Evidence</th>
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<tbody>
<tr>
<td>G1 Ensure commissioning processes take into account the needs and preferences of the local community, and support choice and PPI</td>
<td>1.1 There is patient/public involvement in commissioning decisions 1.2 Contracts and SLAs make reference to PPI and patient experience requirements.</td>
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<td>G2 Ensure there are opportunities for PPI in the services provided by independent contractors</td>
<td>2.1 All GP practices have PPI processes eg a patient participation group. 2.2 Dental, ophthalmic and pharmaceutical practitioners are encouraged and expected to take a PPI approach. 2.3 There is an identified lead for PPI on the PEC.</td>
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</table>
Objective | Action | Position statement | Evidence | Red | Amber | Green
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G3 | Ensure that the whole local community has information about local health services | 3.1 “Your guide to local health services” is produced annually and distributed to every home. It is available in a variety of formats and languages. | 3.2 “Your guide” contains details of PPI activity and how patients/carer/public feedback has led to service improvements. | *(D9a) *(D10) | |

G4 | Support self-management, self-care and prevention | 4.1 There are a range of activities in place to support SM, SC and prevention, either directly provided or commissioned | 4.2 Patients are provided with the opportunity to contribute to the planning of their care. | 4.3 Initiatives are run in conjunction with the voluntary sector to maximise self-management, self-care and prevention | |

SUMMARY AND ACTION PLANNING

<table>
<thead>
<tr>
<th>Section</th>
<th>Key weaknesses</th>
<th>Actions needed</th>
<th>How to take forward</th>
<th>Red</th>
<th>Amber</th>
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<tr>
<td>A</td>
<td>PPI strategy and action plan</td>
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<td>B</td>
<td>Supporting PPI activity and integration</td>
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<td>Systems for patient feedback</td>
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<td>Patient information</td>
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<td>F</td>
<td>Ensuring PPI has an impact</td>
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<td>PCT-specific</td>
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APPENDIX 3

TIMELINE FOR THE PLANNING AND ENGAGEMENT PROCESSES

From May 2005 until July 2006 there have been a succession of planning initiatives in Surrey and Sussex: S4 Sustainable services, Strategic Work Programme and “settings of care” which were designed to provide a vision of what a sustainable healthcare system might look like. This was informed by meetings with both the HOSCs and the PPI Forums.

HOSC INVOLVEMENT

A reference panel of all four HOSC Chairs was established by the SHA to facilitate regular liaison and involvement. In addition, further sessions were arranged with individual HOSCs to cover both Commissioning a Patient-Led NHS consultation and updates on the strategic work programme.

PPI FORUM INVOLVEMENT

A reference panel of PPI Forum members was established to facilitate high level PPI input to the issues being taken forward through the strategic work programme. A flyer was sent to all 100+ Patient and Public Involvement Forum members across Surrey and Sussex via their Forum Support Organisations asking interested members to send in their details. 13 members agreed to join the panel, of which between five and 10 attended each meeting.
A large event was held for all 100+ PPI Forum members across Surrey and Sussex with a keynote presentation from Simon Williams updating PPI Forums about the strategic work programmes, followed by questions and discussion. CPPIH and FSO worked in partnership and answered questions informing them of what’s going on. This enabled them to test out McKinsey’s findings providing insight into potential issues that the wider patient and publics might have. The event itself also provided forum members with personal contacts responsible for the Fit for the Future programme.

At the April meeting of the reference panel, members agreed to disband the panel as they would now be focusing on continuing their involvement at a local health community level. To continue PPIF representation at the strategic level, two members of the panel were nominated to join the Surrey and Sussex wide Programme Board as patient representatives, and two joined the communication and engagement steering group. This ensures community leadership is influencing the planning and engagement processes throughout the programme.

Regular Briefings to Stakeholders

MPs and local authorities were informed and engaged in the ongoing Strategic Work Programme through regular briefing meetings with the SHA Chief Executive and Chair. In addition, specific meetings were organised with Directors of Social Services, and the SHA CE took the opportunity to inform colleagues of the programme at scheduled meetings of GOSE and other LA partnerships. This has been an ongoing feature of the work led by PCT CE and programme leads who have continued to meet and make regular reports on progress and planning to stakeholders throughout the Fit for the Future programme.

“First Steps for Improving Services in Surrey and Sussex”

The above document was produced by the SHA in March 2006. It summarised the findings of the S4 review and how these were developing into the Strategic Work Programme. The document was distributed to key stakeholders (MPs, HOSCs, local authorities, PPI Forums, clinical networks and NHS managers and clinicians) and their feedback was invited. Regular written feedback to the public and the wider stakeholders has also been a feature of the review detailing published documents from this process. (See attached newsletter)

Discussion Document

In May 2006 a discussion document titled “Creating an NHS Fit for the Future” was published by the Surrey and Sussex NHS. This outlined the drivers for changing health services, the proposed direction of travel at a high level and the identified priority areas for each local health community. It invited feedback on the proposed vision for health services, with a freepost address and response form for comments.

This document was distributed widely to stakeholders:

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<th>MPs</th>
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<tr>
<td>Local authorities</td>
<td>PPI Forums, FSOs and CPPIH</td>
</tr>
<tr>
<td>Patient and carer groups</td>
<td>Voluntary organisations</td>
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<td>Local strategic partnerships</td>
<td>Libraries</td>
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It was also published on the newly launched Fit for the Future website, with links from the websites of individual NHS organisations. An on-line feedback form was available.

A total of 6,226 people responded to the discussion, 3,651 signed a petition or campaign letter to protest against the perceived closure or downgrading of a local hospital and 2,575 wrote in with a more detailed response to the issues raised in the discussion document. Of these responses, the majority (81%) were about concerns at the possible closure of St Richard’s Hospital, and most were sent by members of the public (87%).

Each local health community designed a programme of discussion activities to engage local stakeholders and patient/carer representatives in debate about the issues raised by the discussion document. Each person who had phoned, emailed or written in commenting on the discussion document was responded to by either SHA or PCT staff and subsequently sent an update via a Newspaper printed September 2006.

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60 A readers panel informed the content of the website and all materials produced to ensure accessibility.
ONGOING ENGAGEMENT BY THE LOCAL HEALTH COMMUNITIES

East Sussex LHC

Three major stakeholder events were held to discuss the issues outlined in “Creating an NHS Fit for the Future”.

An Outreach Programme meant that the two PCT’s worked hard to attend over 70 local meetings of community/voluntary groups, local authorities, local strategic partnerships and NHS organisations/staff groups to ensure they knew what progress had been made and had an opportunity to inform the thinking. This included meetings of local PPI Forums and the East Sussex HOSEC and meetings with local MPs.

West Sussex LHC

Two major stakeholder events were held to discuss the issues outlined in “Creating an NHS Fit for the Future”, plus a smaller event linked to a regular meeting of the West Sussex Public Partnership Forum.

In addition, the local health community team attended a wide range (around 30) local voluntary/community groups, local authority meetings and local strategic partnerships. This included meetings of PPI Forums and the West Sussex HOSEC and meetings with local MPs.

Surrey LHC

Four major stakeholder events were organised to discuss the issues raised in “Creating an NHS Fit for the Future”.

In addition the local team attended a wide range (around 30) of local voluntary/community groups, local authority meetings and local strategic partnerships. These included meetings with PPIF’s, the Surrey HOSEC and local MPs.

Brighton and Hove LHC

Brighton and Hove LHC focused on using existing community engagement mechanisms to discuss “Fit for the Future” issues with local stakeholders. These mechanisms are well developed following previous consultation on “Best Care, Best Place”. The local team attended a range of local community/voluntary groups and local authority meetings, including meetings with PPI Forums and the Brighton and Hove HOSEC. They also set up small focus groups as a means for discussing any issues raised by the programme for local people.

SHA Level Engagement

Although stakeholder involvement was led locally, the SHA continued to liaise with key stakeholders such as MPs and HOSECs.

In order to provide further independent and expert guidance to the involvement process, the SHA also established a “Patient and Public Involvement (PPI) Expert Panel”. This consisted of representatives from national organisations and people with recognised expertise in the field of service reconfiguration, and representatives from local HOSECs and PPIF’s were also invited to join. The membership from national organisations is as follows:

<table>
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<tr>
<th>Name</th>
<th>Affiliation</th>
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<tr>
<td>Prof Bob Sang (Chair)</td>
<td>PPI advisor to Fit for the Future</td>
</tr>
<tr>
<td>Tim Gilling</td>
<td>Centre for Public Scrutiny</td>
</tr>
<tr>
<td>Jenny Deville</td>
<td>DH, author of “Strengthening Accountability” and PPI lead, South East London SHA</td>
</tr>
<tr>
<td>Pippa Hague</td>
<td>DH PPI team and PPI lead, East of England SHA</td>
</tr>
<tr>
<td>Chris Howgrave-Graham</td>
<td>Advisor to DH Reconfiguring Hospitals programme</td>
</tr>
<tr>
<td>Martin Houghton</td>
<td>Independent Reconfiguration Panel</td>
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</table>

The purpose of the panel was to provide an expert sounding board for engagement plans and access to national best practice and policy on engagement involvement consultation and its possible repercussions. Programme leads also attended the Future Health Network to learn from their peers and best practice in large scale service reconfigurations in Bristol and Manchester etc.

Feedback from Discussion Phase

All the feedback and correspondence received during the initial discussion phase was logged centrally by the SHA and passed to independent analysts TwoCan Associates who have produced a report summarising the key themes and issues raised by stakeholders.
FURTHER DISCUSSION (AUGUST—PRESENT AND ONGOING)

This stage moved the discussion on from drivers for change and a high level vision into the specifics of what this would mean in terms of service change in each local health community. During this stage stakeholders are being engaged in discussion about the potential scenarios for the configuration of acute care as well as consideration of what community based services would be needed to support this.

Co-design—August to January 2007

During August each local health community held a “co-design” workshop facilitated by the PPI advisor to Fit for the Future, Prof Bob Sang. These workshops brought together small groups (c20) key stakeholders such as PPIFs, voluntary groups, patient representatives (including “campaigners”) with clinicians and managers to look in more detail at the potential change scenarios emerging from work on local sustainability plans. The ground rules for co-design require everyone to listen respectfully, and to contest the evidence from the perspective of improvement and a person-centred, service-focused rather than building-focused, value base.

Thus the challenge facing the local health communities can be described as an “effectiveness improvement cycle”.

Co-Design is not new. It has deep roots in the work of the Tavistock Institute (Lewin, Emery, et al), and a strong evidence base, linked to Action Research and Action Learning (Revans, Bessant, McGill, etc). It is a method for addressing tough “trade-offs”. Locally, the Kent and Medway Specialist Services Review and the Central Sussex Partnership Programme (CSPP) both achieved a constructive, consensual resolution of initially contentious service change proposals. The four health communities have had regular iterations of the co-design events to take people’s collective thinking forward through the need for change, the potential areas of what within each community, and latterly what those scenarios might look like in terms of service changes and proposals which require a wider consultation.

Deliberative events—September

As part of this engagement process four deliberative events were held, one in each Local Health Community area. Vision Twentyone61, a company specialising in consultation and public involvement was commissioned to recruit, design, manage and facilitate these events. A representative sample of members of the public from each area, who had not previously played and part in the discussions were recruited to participate in one day workshops where they listened to presentations from the perspective of clinicians, managers and patients. Having heard the case for change they had the opportunity to deliberate on the issues in small groups.

The aims of the events were as follows:

— To invite a local sample of individuals to participate in a discussion about how sustainable healthcare services could be provided for their community.

61 The use of independent contractors has been used to ensure a robust quality assurance is present throughout, and reassure participants that no bias can affect the outcome of any part of the discussions or subsequent plans.
— To give participants an opportunity to talk about issues that affect their lives and to tell the NHS in Surrey and Sussex how they think things can be changed for the better.
— To create an “open—two way dialogue” explaining the constraints of resources, clinical standards and modern medical practice which will need to be taken into account when decisions about these changes are made.

Improving understanding and raising awareness about the need for change

Having heard the presentations (and worked through deliberative exercises in small groups) the majority of participants felt that they understood the need for change and were in favour of a community focused model of health services with specialist centres for critical care remaining at fewer hospital sites.

One participant noted: “From what we have heard through the presentations, if the services promised to be delivered in doctors’ surgeries and Walk-in Centres are actually implemented the benefits will be great.”

When asked participants were asked “why” they took part in the event, reasons given were because: they wanted to find out what might happen to local hospitals. Another participant noted that following the telephone survey, they were interested in seeing or hearing “both sides”. The perceived downgrade of services and issues around cleanliness are also points that encouraged people to take part. They wanted to take part in the debate and contribute to the discussion around the future of the NHS. Ultimately they were interested in having their say. Above all: “the health service is vital, even more so as one grows older.”

There continues to be a gap in understanding between those who have worked with the health service to improve services, and those who learn about the NHS through media coverage and the rumour mill generated by NHS staff.

Evidence submitted by the Southwark Patients Forum for Primary Care (PPI 54)

What is the purpose of PPI?

1. We are all Patients, or potentially so. Therefore, PPI is the means by which those who use the services provided, and pay for them via taxation, can:
   — influence the decisions of both Commissioners and Providers;
   — help determine local priorities between services when funds are not available to meet all possible requirements;
   — scrutinise the quality of the services and the way in which they are being delivered;
   — call those Commissioners or Providers of services to Local Account, when that is necessary;
   — influence the local process of change when that follows from National decision of the Department of Health;
   — have access to NHS facilities and/or Services and physically inspect what is being provided; and
   — exercise a process of discipline against bureaucracy or wrongful use of powers by virtue of the right to demand information to a fixed timescale and to Inspect—it is not the inspection of itself that is important but that the power exists to conduct one . . . which serves to focus minds when replying to questions.

2. PPI, and PPI Forums in particular, substitute for Direct Representative Democracy in a situation in which it is acknowledged that an Appointment System will always act to reduce legitimacy.

3. The potency will always be at local level, but that potency can be enhanced by an indirectly elected system of Regional and National Forums.

4. It follows that there must be a funding level that permits adequate communication of the existence of PPI to all Patients so as to:
   — ensure that there is awareness of such organisation;
   — understanding of the role of PPI, and Forums;
   — encourage the use of the local Forum as the most relevant resource for users to communicate both there aspirations and desires for local health provision and their satisfactions, or otherwise, with what is being provided (although this should not extend to individual complaints unless an appropriate specialist secretariat was provided); and
   — allow of the Forum reporting back to its public what has been achieved. Such achievement, continually monitored and measured, would be a powerful contribution to improving legitimacy in the absences of direct elections—the lack of such resources and activity has been an undoubted weakness which means that PPI Forums could have been even more successful than has largely been the case.
5. It should be noted that Local Government Scrutiny Committees cannot substitute for PPI because:

- Local Government Systems introduce an element of Party Politics which is disadvantageous in a monitoring function in which it is wished that all of the public should be directly involved.
- Forums have the Independence which Scrutiny Committees lack.
- In Social care, Local Government Commissioners and Providers have a conflict of interest with a Scrutiny Committee, particularly if the issue became politically involved.

All of the a foregoing presumes the existence and operation of an Involvement Model as is practiced by Southwark Patients Forum.

What form of Patient and Public involvement is desirable, practicable and offers good value for money?

6. Clearly, in a Democratic System of Government there is no substitute for directly elected Authorities (on the US model for some forms of Government) that are directly charged with determining Health & Social Care Provision, Commissioning it . . . and even extending to raising the funds to pay for that provision. However, such change is not on the Agenda and this response takes no account of it.

7. Accordingly, it is proposed that, within an Appointed System, the present arrangement of PPI Forums serve needs best, although there is a case for some change which is described in the response to the third question.

8. This argument is subject to the following:

- an operational style that embeds consultation into the management decision making process of the NHS Trust to which the PPI Forum relates;
- the recognition by that Trust that Consultation begins when ideas are first mooted and all options are open . . . not when decisions have already been taken and when Consultation becomes defensive of those decisions;
- the achievement of the maximum possible legitimacy as is described in para 2.4;
- the PPI Forum being proactive in representing patient interests, hopefully, assisted by a flow of input from Patients and Public who are aware of the Forum and understand its role;
- Patients and Public believing that its input to the Forum will have a positive result which will be reported back to them . . .;
- the resources being available to allow of “Reporting Back” being achieved in a situation which:
  - editorial in local media—particularly in big cities—cannot be guaranteed; and
  - local Voluntary Networks are inadequate in reaching the public at large.

Even so, some “reporting back” is better than none: so this lack, although undesirable, serves to minimise achievement rather than to deny of it.

The operating system of the Southwark Patients Forum implemented with the fullest cooperation of the Southwark Primary Care Trust

9. The objective of the operating system, worked out during 2006, embeds the work of the Forum into the day to day activities of the NHS Trust at both strategic decision making level, and policy implementation.

There are five components:

- Meetings with the Executive Directors of the NHS Trust which take place six times per year in advance of Trust Board Meetings.
- Agendas are two way and allow of discussion of Board Papers . . . before they are submitted to the Board (in this way, the Forum is treated pari passu with Non Executive Directors).
- Direct access to Trust Managers below Director level in order to explore policy implementation.
- A Lead Members’ Brief System with the objective of extending both the breadth and depth of the Forums involvement in the work of the NHS Trust.
- This has been agreed upon by all Members of the Forum who take personal responsibility for achievement within their Briefs and are expected to be proactive.
- The remit of the Forum has been shared among the Forum members according to their interests and area of expertise.
- Members have freedom to act with the full authority and backing of the Forum within their brief.
- Members report back to the Forum at meetings in the form of written reports which are discussed and endorsed.
— Any changes to Lead Member’s Briefs are discussed and agreed at Forum meetings.
— The NHS Trust, at Executive Director and Management levels, are kept informed of these Briefs.
— Forum Members being full members of Operating and improvement Groups such as Urgent Care, District Nursing and GP Referral (in which the Forum Member sits with GPs considering Demand Management which is significant in impacting upon Patient interests).
— Continuation of presence at Public Trust Board Meetings with a “seat at the table” and the right to speak and ask questions, pari passu with Non Executive Directors.

At the present time, The patients Forum and The NHS Trust are jointly seeking media communication of this partnership working, using the resources of the Trust, in, an effort to interest the public at large and so enhance the legitimacy of the Patients’ Forum’s involvement.

Why are existing systems for Patient and Public Involvement being reformed after only three years?

10. There is a case for change but not to the extent that the Government has proposed which initially removed all powers of Inspection and even now removes the direct link with an NHS Trust that is critical to any process of monitoring and local calling to account.

11. What previously has allowed of:
— a right to an answer/information in 20 days put to the related Trust;
— attendance, in many cases with a “seat at the table”, at Board meetings; and
— inspections of all establishments (but now to be limited to NHS facilities but NOT Private Sector facilities—which of itself arouse suspicions) will now be reduced to an arms length relationship to Commissioners to a timescale and interface that is bound to be longer and very impersonal.

To this extent, what the Government states to be A Stronger Local Voice in fact becomes a very much Weaker Voice.

12. The change that is valid relates to Hospital Trusts since it is an undoubted fact that Foundation Hospital Membership Councils/Governing Bodies do provide for duplication.

13. This does not apply to Primary Care Trust Forums and one simple change could remedy the situation. The Government has gone to great lengths to align PCT areas with Local Government areas to allow of joint Health and Social Care delivery . . . and has made much of the co-terminosity.

14. Therefore, Southwark Patients Forum proposes that a local LINk be associated with its local PCT and Social Care Organisation with the powers to operate in the same way—as PCT Forums do now (including the right of inspection of Private Sector Providers. . . .hopefully using the model of Involvement developed in Southwark.

How should LINks be designed?

15. As suggested in para 4.5, LINks should, de facto, take over the role of PCT Patients’ Forums and have the same level of remit and independence (but include Social Care).

16. Membership and appointments should be via a Commission which should be administrative only. . .a larger form of the current support organisations with no role in policy or determining practice.

17. However, it should be noted that there is a conflict of interest between LINk membership and the activities of some Voluntary Sector Organisations who may also be Providers. This conflict is enhanced if their representatives are Executives rather than Volunteers.

18. Funding must be sufficient to support the work including that required to enhance legitimacy (para 4).

19. The area of focus, statutory powers and relationship with local Health Trusts has been defined above. Since Hospital Trusts are but one of a number of Providers there is no reason to treat them in any other way . . . their internal democracy can be delivered by Members’ Councils as all hospital will eventually become Foundation Trusts.

20. There should be both Regional and National Bodies elected from local LINks representation.
How should LINks relate to and avoid overlap?

LA Structure (including Scrutiny Committees)
21. This has been dealt within para 5.

Foundation Trust Boards and Members Council
22. See response at paras 12 and 19.

Inspections (including The Health Care Commission)
23. Present arrangements for Forums are satisfactory since HC Representatives are appointed to engage with Forums and often attend meetings. It should be the duty of the Chair to seek to enhance this relationship.

Formal and Informal Complaints Procedure
24. If this means Patients individual Complaints these should be handled by the PCT. ...overseen by the Healthcare Commission.

This would be subject to:
— The PCT overseeing all Complaints in relation to their Commissioning including those within GP and Hospital Systems (both NHS, Voluntary and Private Sector).
— The PCT should have the statutory duty to coordinate complaints and issue a consolidated report—open to discussion—with the LINK.
— The LINK should use this Report as a Management tool in assessing the quality of service delivery and of any need for investigation within its inspection powers.

This is not currently possible for the PCT Forums (or for that matter PCTs) since Complaints disappear into PALS, GP Systems and Hospital System. There are no powers of consolidation within present NHS Regulations—only a Developmental Annual Health Check Standard exists and this is not being pursued as a priority in the current year.

Section 11 etc powers
25. A LINk should have the power to determine a S11 criteria which was specifically ruled and in the North Derbyshire Judicial Review.

Barry Silverman
Chair, Southwark Patients’ Forum for Primary Care
January 2007

Evidence submitted by St Mary’s NHS Trust PPI Forum (PPI 145)

1. What is the purpose of patient and public involvement?

The purpose of patient and public involvement is so that members of the public in a diverse society can get there views across to the government as well as local NHS trusts and doctors practices. They also should be entitle to a say on how vast sums of money are spent on there behalf.

2. What form of patient and public involvement is desirable, practical and offers good value for money?

The most desirable form of patient and public involvement is the unpaid volunteer as they are more likely to be independent. Having said that in today’s society to encourage disadvantage groups, single parents and to attract the right caliber of people we might need to increase expenses to cover childcare and time spent in meetings.

Trying to demonstrate valve for money is very difficult because of connecting outcomes to processes and structures.

The Government needs to define what it wants a PPI system to deliver.
3. **Why are existing systems for patient and public involvement being reformed after only three years?**

One reason given for reforming the patient and public involvement system is that the government wants to widen the involvement of the public in health and social care although there have been no clear guidelines on how this is going to happen.

Another was that the Forums were ineffective and the PPI will need to be more involve with the commissioning. This may be true but you cannot guarantee that the LINKs will be more effective and if Forums members disappear you will have the same situation as the change over from CHCs to Forums.

4. **How should LINks be designed, including**

   — **Remit and level of independence**
     The remit should cover all health issues from commissioning to providing. The LINks should be independent from the department of health and local authority control.
   
   — **Membership and appointments**
     Membership should be open to all with rules on conflicts of interest and to ensure that organisations with a vested interest in single health issues don’t dominate committees.
   
   — **Funding and support**
     Funding should not be less than it is at present and control of the budget given to the LINks. This could be base on the population with separate funding for deprivation, rural or other reasons. The support for the LINks should be provided by a local organisation providing they are not a health pressure group. They should also be able to provide office, computers and telephones.
   
   — **Areas of focus**
     The LINks should be able to look at any area of health they deem appropriate.
   
   — **Statutory powers**
     The powers should not be less than that of the forums with some areas being strengthened to give access to any contracts for the provision of healthcare. Trust should not be allowed to use business confidentiality to stop LINks viewing contracts.
   
   — **Relations with local health trusts**
     Forming a good working relationship with the local health trusts is desirable so that you work together in improving services to the patient.
   
   — **National coordination**
     Ideally the organisation should be built from the bottom up. The main thrust should be local. If regional and national bodies are needed the remit for the person charge with setting them up should be to form regional and national bodies within 12–18 months by elections from local networks.

5. **How should LINks relate to and avoid overlap with**

   — **Local Authority structures including Overview and Scrutiny Committees**
     The LINks should have a voice on the OSC but not be part of it.
   
   — **Foundation Trust boards and Members Councils**
     Again LINks should have a voice on the Members Councils and Trust Boards.
   
   — **Inspectorates including the Healthcare Commission**
     The LINks should work closely with the Healthcare Commission and be consulted on areas that are failing.
   
   — **Formal and informal complaints procedures**
     The ICAS side of the complaints procedure should be strengthen and given greater prominence.

6. **In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?**

   There should be a consultation procedure between the trusts, local authorities and LINks for all changes at a local level which would have an effect on patient’s health and social care.

   Roy Oliver
   Chair, St Mary’s PPI Forum
   10 January 2007
Evidence submitted by Tower Hamlets PPI Forum, Barts and the London Hospital PPI Forum and the East London and the City Mental Health PPI Forum (PPI 70)

The joint Patients & Public Involvement Forums of Tower Hamlets, Barts and the London Hospital and the East London and the City Mental Health wish to make known that they consider the following points of paramount importance to the setting up of effective patient and public involvement in health and social care. The name LINks seems to be already decided, although we think something more clearly related to health and social care would be desirable. However, we will use the name in our comments.

- LINks must maintain independence and allow for participation at all levels across health and social care issues.
- LINks to retain right of inspection, both NHS, local authority and independent providers.
- LINks to have the ability to encourage, listen to and take note of the local community comments on services.
- LINks must ensure programme has close links with Trusts, social services, voluntary sector and community groups.
- A national body is needed to oversee all LINks and share best practice. Also to provide a centre for local LINks to feedback information on topics that could be of national interest and to give greater credibility and unity. It was suggested that this could be the Healthcare Commission (HCC).
- Resources; need to be ring-fenced, to include enough for two staff and an office and a discretionary budget for research and projects. It was suggested that budgets should be on a 5 year basis and should total around £200,000 per year per borough.
- A properly resourced and responsive high public profile is required.
- Every Local Health Authority to be required to have an Overview and Scrutiny Committee dedicated to Health and Social care which includes professionals with the relevant knowledge to make a meaningful contribution.
- LINks members need to get involved in local services and committees, and encourage special focus groups for the Acute and Mental Health Trusts, the PCT and local authority services.
- Groups need sufficient time to disseminate information to members and feed back to Health Select Committee.
- Local interest groups providing services that get involved in LINks should be required to declare any interests in Local Government and NHS contracts.

Tower Hamlets PPI Forum
Barts and the London Hospital Forum
East London and the City Mental Health PPI Forum

January 2007

Evidence submitted by the UK Clinical Research Collaboration Patient and Public Involvement Project Group (PPI 91)

1. Executive Summary

1.1 The UK Clinical Research Collaboration (UKCRC) is a partnership of key organisations involved in shaping the clinical research environment in the UK. All the UKCRC Partners have their own approaches to patient and public involvement however they have committed collectively to engage patients and the public in the clinical research agenda. The objective is to work in partnership with key stakeholders to embed patient and public involvement clinical research activity.

1.2 The UKCRC is working to develop coordinated solutions to some of the more challenging issues in patient and public involvement in research. Rather than fragmented responses and/or duplication of effort we are working to ensure that limited resources are used effectively in pursuit of patient and public benefit.

1.3 Building a rigorous evidence base to underpin the future development of patient and public involvement in the NHS, including research, is of vital importance. To improve patient and public involvement in the NHS a more coordinated approach to future research is required and both the UKCRC and the UK Clinical Research Network (UKCRN) are committed to working on this agenda.
2. Introduction

2.1 The UK Clinical Research Collaboration (UKCRC) was established in 2004 in the wake of the Report of the Research for Patient Benefit Working Party [1] and to effect the changes necessary to make the UK a world leader in clinical research for the benefit of patients and the public. The strength of the UKCRC is that it brings together key organisations (including main funding bodies, academia, the NHS, regulatory bodies, industry and patients) who work in partnership to tackle complex and long-standing issues that cannot easily be addressed by individual organisations alone.

2.2 In two years the UKCRC Partners have developed effective new ways of working together, agreed a broad joint agenda and undertaken an ambitious programme of work [2]. Working in partnership to develop coordinated solutions to shared problems avoids fragmented responses and/or duplication of effort and ensures that limited resources are used more effectively.

2.3 The UKCRC takes a dual approach to working with patients and the public. It has established:

— A Public Awareness Task and Delivery Group to develop ideas and lead projects around raising public engagement with the value of clinical research and clinical trials. Initiatives include producing publications for members of the public and developing resources for teachers (http://www.ukcrc.org/patientsandpublic/publicawareness.aspx).

— A Patient and Public Involvement Project Group to provide an arena for Partner organisations and other stakeholders with an interest in patient and public involvement in research to work on a shared agenda for action. The current agenda developed by the Group is tackling some of the enduring barriers to patient and public involvement in research (http://www.ukcrc.org/patientsandpublic/patientandpublicinvolvement/currentprojects.aspx).

In Respect of the Issues Raised by the Committee

3. What is the purpose of patient and public involvement?

3.1 Patient and public involvement in the NHS is an emerging field and clinical research is an area in which patient and public involvement has been developing in the UK over the past 15 years led initially by the HIV/AIDS community and followed in other healthcare areas. With the establishment of the UKCRC and the development of the UK Clinical Research Network (www.ukcrn.org) further “topic specific” and more general approaches are now being infused with patient involvement.

3.2 Many of the facilitators and barriers that are key in either supporting or impeding the sustainable development of patient and public involvement in research are equally relevant to the field of patient and public involvement in the NHS. Research is a core activity carried out by and in the NHS contributing to the development of treatments, to the delivery of NHS services and also to developing knowledge and understanding of patient and public involvement [3].

3.3 There are many potential benefits to involving patients and the public in clinical research [4–10]. A major purpose of patient and public involvement in research is to add value to the research that is undertaken, which can in turn lead to the implementation of improvements in treatments and services that are made available to the public. This has also been seen in other areas of work in the NHS [11].

4. What form of patient and public involvement is desirable, practical and offers good value for money?

4.1 There is a growing body of literature that describes models of patient and public involvement in research. These are beginning to be drawn together [12] so that issues such as desirability, practicality and value for money can begin to be addressed. Guidance documents formulated around examples of good practice are also becoming more common [13–14].

4.2 However this field has suffered from a fragmented approach which has resulted in evidence often being anecdotal in nature. A systematic review of evidence in this area has not yet been undertaken. In order to improve patient and public involvement in the NHS more research is required to understand what does and what doesn’t work. The work of the NHS Centre for Involvement (http://www.nhscentreforinvolvement.nhs.uk) should be a significant step forward. The UKCRC is contributing to work in this field by collaborating with other organisations to develop a more coordinated approach to identifying and building the evidence base in research.

4.3 The UKCRN coordinates the work being undertaken to develop and strengthen the NHS infrastructure for the delivery of clinical research in the UK. UKCRN offers an important opportunity to develop good practice and gain a better understanding of public involvement in research. The six thematic research networks (including cancer which has submitted a separate memorandum to the Inquiry through the National Cancer Research Institute Consumer Liaison Group) are at the heart of the patient and public involvement element of this work.
4.4 An example of current work is that of the UKCRN working closely with the National Institute for Health Research to put in place IT systems which facilitate patient and public involvement. Systems will allow one-to-one, one-to-group, and many-to-many sharing of ideas, messages and key documents on both a regular and ad hoc (project) basis. The system can bring together involved patients and public with health researchers and clinical trialists. The development project (COMMIT) is leading to a pilot project with the National Cancer Research Institute Consumer Liaison Group and the patient/public group involved with one other themed network during first half of 2007 and more widespread implementation is planned for later in 2007.

4.5 The processes and methods used to involve patients and the public within the UKCRC structure will be reviewed and activities evaluated to inform improvements in practice. This can also provide future evidence about a range of issues including value for money in patient and public involvement.

5. Conclusion

5.1 If the public are to become meaningfully engaged in the key policy issues that confront the NHS then the development of successful methods of patient and public involvement will provide valuable opportunities for the NHS to engage with patients and the public and gain a better understanding of issues of interest and concern. Patient and public involvement is a relatively new area of NHS interest and patient and public involvement in research is an important element in its continued development. Ultimately it requires greater focus and attention on the part of us all to ensure that we maximise the full potential of patient and public involvement in adding value to the NHS as it evolves.

Roger Wilson
Chair, UK Clinical Research Collaboration, Patient & Public Involvement Project Group
10 January 2007

REFERENCES

[12] For example, invoNET (http://www.invo.org.uk) is a network of people working to build evidence, knowledge and learning about public involvement in NHS, public health and social care research. It is developing a library of references and documents whose primary focus is a research analysis or reflective analysis of public involvement in NHS, public health or social care research.
Evidence submitted by UNISON (PPI 105)

1. INTRODUCTION

1.1 UNISON is the major union in the health service. Our health care service group represents more than 400,000 employees in the NHS and staff employed by private contractors, the voluntary sector and general practitioners.

1.2 UNISON has a proud tradition of working with patient groups and through Community Health Councils to aid the development of local health initiatives, and therefore welcomes the opportunity to put forward comments and ideas to this inquiry. We submitted a reply to the Department of Health’s A Stronger Local Voice consultation in September 2006.

1.3 The UNISON/Oxford West & Abingdon composite passed at Labour Party Conference in 2006 included action point 5, “the Government to ensure that structures for patient and public involvement work effectively and that the public have a genuine say over commissioning and configuration decisions.” This indicates the high priority UNISON attaches to this expanding area of health policy and we are encouraged that the Health Secretary has responded quickly by establishing a new Stakeholder Forum to expand consultation and dialogue with the unions.

2. What is the purpose of patient and public involvement?

2.1 Public and patient involvement (PPI) serves an increasingly important purpose for a number of reasons. Most importantly, in recent years we have witnessed the gradual undermining of local democratic accountability in the health service. The plan is for all hospitals to have the chance to become foundations trusts by 2008. The greater autonomy from traditional scrutiny that foundation trusts enjoy has made a mockery of the claim that they would increase the accountability of hospitals to their communities. Likewise, the increasing involvement of the private sector, where the main responsibility of companies providing services is to their shareholders, runs contrary to building a stronger voice for patients and the public.

2.2 PPI should also be a driver of greater equity in service provision by allowing the disadvantaged within society a chance to voice their healthcare needs that they may otherwise not have had.

2.3 In the longer-term, PPI should also be a means of boosting public health and, by extension, safeguarding the future of the NHS. If local populations become more actively involved with their own healthcare there is a better chance of boosting awareness of healthy lifestyles. The Wanless report argued that this was the only way to ensure the future economic sustainability of the NHS.62

2.4 The Government and other commentators are right to emphasise the rising public expectations of the health service.63 This has been brought about in part by the marketisation of the NHS in which patients are treated increasingly as consumers. Faced with constant reference to the mantra of “patient choice” it should come as no surprise that patient and publics are ever more exacting in their desire to achieve the type of health service they want.

3. What form of patient and public involvement is desirable, practical and offers good value for money?

3.1 UNISON wants to see the new system provide a real opportunity for local communities to have a proper say in who delivers their healthcare, particularly where controversial decisions about outsourcing services are concerned. An excellent recent example of this is the situation within North East Derbyshire PCT where local resident Pam Smith was left with no option but to go to the High Court, and subsequently the Appeals Court, to challenge (successfully) the decision to allow United Health Europe to take over the running of GP services. In the future, proper public involvement in the decision-making process needs to take place before NHS contracts are awarded, with meaningful involvement throughout rather than tokenistic consultation towards the end.

3.2 The new local involvement networks (LINks) need to be properly independent and have the ability to take action. More than this, there needs to be a recognition that consultation processes will only produce genuine accountability if the final decisions actually reflect the wishes of the local population; a duty to consult is different from a duty to act on the results of consultation.

3.3 Strengthened forms of collective PPI which view patients as citizens should be favoured over the narrow consumerist logic of the “patient choice” agenda. Health is more than a commodity to be consumed by users; it requires patients to be involved in shaping the form their healthcare takes from the start of the decision-making process and through rights of access derived from the public ownership of the health service. The choice model does not encourage democratic accountability as patients effectively shape services through their actions as consumers. Unfortunately, as the recent Involve/NHS National Centre for Involvement report on health democracy has acknowledged, the choice agenda “potentially undermines the

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argument for user involvement as a more egalitarian mechanism for securing these outcomes.” The current marketisation of the NHS mitigates against the type of collective patient and public involvement that LINks are expected to undertake.

4. Why are existing systems for patient and public involvement being reformed after only three years?

4.1 It is important that this question has been asked. UNISON opposed the break-up of Community Health Councils (CHCs), which allowed patients and the public to be meaningful stakeholders in the delivery of their healthcare. Whilst an acknowledgement that the current system of patient and public involvement may need sharpening is welcome, the decision to abolish the Commission for Patient and Public Involvement in Health (CPPIH) has been greeted with dismay by staff at the CPPIH, which has only been in existence since 2003. Some staff working for the Commission were previously employed by CHCs, and having been through one set of changes three years ago, they have since experienced more restructuring (between September 2005 and February 2006), and now the latest proposals have left them facing a third round of reconfiguration in as many years.

4.2 The dissolution of CHCs and now the proposed abolition of the CPPIH means not only the loss of experienced and skilled staff, but also effectively wipes away at the institutional level any collective understanding of the advocacy and rights processes of the health system. This will require many years of renewal and the re-equipping of staff and systems to put right.

4.3 In the wider context, with the decision to abolish the CPPIH originating in the Arms Length Body Review, the latest set of proposals provide a further opportunity to review the validity of a process which is already causing massive disruption for staff at NHS Logistics and elsewhere.

4.4 The abolition of PPI forums was announced just eight months after they were set up, so whatever the failings of the current system it is hard to argue that it has been given proper time to bed down. The apparently continuous nature of the current health reform programme is not allowing proper time for discussion and pilot-testing, with new set-ups abandoned or reconfigured before they have taken root. Staff working in these services are continually obliged to adapt to new initiatives and, in the worst cases, forced out of the system altogether. These changes are part of a wider trend in which a Government intent on introducing one reform after another finds itself in the position of deriding its own earlier reforms. This approach is allowing critics of the NHS to portray all health reform as a failure and creating a false impression with the public as reflected in increasingly sceptical opinion polls.

5. How should LINks be designed?

5.1 UNISON is glad to see that the Department of Health has responded to concerns (raised by UNISON and others) about LINks’ powers of access. UNISON members involved in patient forums had voiced concern that the original A Stronger Local Voice (ASLV) consultation meant the possible loss of statutory powers to visit services, a valued means of gathering at first hand the operational reality of service delivery and the patient experience. UNISON is therefore glad to see that the new Local Government and Public Involvement in Health Bill makes provision for a duty on service providers to allow LINks to enter and view premises. A major concern, however, is that the list of organisations that constitute “services-provider” does not explicitly include private sector companies. This is an important omission that needs to be remedied. The power of LINks could be extended still further to allow them access to contracts drawn up with independent providers of healthcare services, as a means of closing the accountability gap that has been opened up by the involvement of the private sector.

5.2 Although the Bill contains very little detail on the exact design of LINks, there are positive areas contained within ASLV and the subsequent Department of Health reply to responses. The system should allow for a more joined-up approach covering health and social care; it should allow the voluntary sector to contribute knowledge and expertise rather than simply providing services; the loophole that meant the public did not have to be consulted on changes to existing services would be closed; and, importantly, the proposals contain an explicit reference to consulting with all staff who may be affected by changes to local health services.

5.3 But there are a number of areas where the proposals for LINks that have emerged so far could be redesigned or where a rethink may be necessary. A major area for concern is the organisational make-up of LINks. The community and voluntary sector has much to offer in terms of innovation and plugging those gaps in provision which the NHS cannot, such as Marie Curie’s hospices. The expertise and knowledge such organisations will bring to LINks will also be valuable. With the Department of Health increasingly keen for commissioners to procure services through voluntary organisations and social enterprises, however, there is potential for a serious clash of interests. The Government’s reply to the ASLV responses states that “these issues are commonly dealt with by voluntary organisations that are both lobbying groups and also provider

64 Involve & NHS National Centre for Involvement, Health Democracy: the Future of Involvement in Health and Social Care, 2006, p10
65 Local Government and Public Involvement in Health Bill, Part 11, 156—Services-providers’ duties to allow entry by local involvement networks.
of services.”66 This may be so, but being a lobbying group is different from acting as a scrutineer (as well as a provider of services) which is the situation voluntary organisations could find themselves in. Such a situation would be magnified further if these organisations have additional responsibility as the hosts of LINks. If these plans do go ahead in their current form, then a robust system of checks and balances must be brought in to ensure fair play. Alongside adopting existing good practice examples such as Registers of Interest, as referred to by the Government.67 Similarly there is a potential question mark hanging over the independence LINks will have from their sponsoring local authorities. Careful monitoring and transparency will be needed.

5.4 Plans for LINks to cover local authority areas should provide benefits in terms of an overview of the referral and movement of patients between different parts of local health and social services, but there are potential drawbacks as well. UNISON is concerned that the more diffuse nature of LINks could mean it is more difficult for staff organisations and other bodies to engage in a coordinated way. The current system of forums based at institutional level arguably makes it easier for patient and publics to hold decision-makers to account. In a geographically large area covered by one LINk the danger is that individuals are discouraged from taking part due to the practical realities of travelling larger distances. Similarly it may be harder for people to relate to the health needs of an area that is further from the part of the world of which they have direct experience.

5.5 At the most fundamental level, the health reform agenda may mean that current plans for the design of LINks end up being an inappropriate vehicle for evaluating and scrutinising the commissioning and provision of healthcare. Following on from point 3.3 above, this is due to an apparent contradiction in Government policy which on the one hand is encouraging the local involvement aspect of LINks, but at the same time forging ahead with market-based reform of the NHS which favours larger and more centralised supply mechanisms, such as fewer and bigger PCTs and hospitals.

5.6 Equality is one area where it remains to be seen whether the proposals have gone far enough. In ASLV the Government called for a more systematic approach for delivering a stronger voice at the national level, in part to promote equal access for less resourced groups. LINks need to be carefully resourced to avoid exacerbating current health inequalities. Equality issues are referred to in the Department of Health response to the ASLV consultation but it is not clear how the new arrangements will guarantee that disadvantaged or vulnerable groups will have a fair opportunity to be involved, as contrasted with those with experience of making the system work for them. It is important that the new arrangements are equality-proofed before being implemented.

5.7 There are many other areas where greater clarity is needed. For example, how will members of LINks be recruited, supported and developed in their roles? And the question of funding is very important: it remains to be seen how effective LINks can become with the Government not planning to ring-fence the funds that local authorities can spend on LINks. If this is not changed, the new system will need to be monitored very carefully to ensure that LINks become properly viable organisations.

6. How should LINks relate to and avoid overlap with Local Authority structures including Overview and Scrutiny Committees, Foundation Trust boards and Members Councils, Inspectorates including the Healthcare Commission, Formal and informal complaints procedures?

6.1 As referred to above, it is possible that the independence of LINks may be compromised by aligning more closely with the work of local authorities, including Overview and Scrutiny Committees, so the new system needs to be careful to ensure a clear delineation of roles and responsibilities between the two.

6.2 It makes no sense for informal complaints procedures to exist separately from the more formal work of patient and public involvement. The one can inform the other and vice versa. The new LINks should at the least be informed of the content of complaints, if not the personal details of those making complaints.

7. In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

7.1 In recent years there have been too many important decisions made about outsourcing and local reconfigurations without the right amount of public consultation, of which the Pam Smith case is just the most high profile recent example. Public consultation needs to take place earlier in the proceedings so that proposals for changes are no longer seen as a fait accompli with mere lip service paid to consultation.

7.2 The Government’s current proposals for PPI could be strengthened by including the need for contracts with all providers to include a requirement to involve and consult patients and public throughout the decision-making process. The earlier commitment to strengthen Section 11 (contained within ASLV) needs to apply equally to practice-based commissioners and non-NHS providers.

67 Ibid.
7.3 Furthermore, the Government needs to look carefully at commercial confidentiality and the fact that financial matters in the private sector are apparently exempt from Freedom of Information requests. This needs to be addressed or the perception that commercial interest is taking precedence over the public interest will intensify.

7.4 Recent suggestions that partnership working between the Government, employers and unions should be rolled out to strategic health authority and organisational level are very welcome. Within this the Government needs to ensure a more rigorous application of the requirements under Section 11 obliging NHS organisations to involve and consult patients, public, staff/unions and overview and scrutiny committees in decisions affecting the operation of services. As an example, where deficits are occurring and are leading to job cuts, the obligation to consult should act as a vehicle for ensuring that staff relocation packages are organised before announcements are made about closures or reconfigurations.

8. CONCLUSION

8.1 More information is still needed on some of the specifics around how LINks will actually operate. The proposed new system does have some advantages but there are also problem areas that need to be addressed in terms of institutional independence. A wider question that needs to be considered is just how effective the new LINks will be, operating as local organisations in a healthcare environment increasingly driven by a centralising market-based dynamic.

8.2 With the Local Government and Public Involvement in Health Bill expected to have its second reading in January 2007, it is imperative that the Commons Health Committee lobby the Government to, at the very least, allow the Committee to report the findings of its current Inquiry before the Bill becomes law.

Karen Jennings
National Secretary (Health Care), UNISON
January 2007

Evidence submitted by University College London Hospital Foundation Trust PPI Forum (PPI 75)

WHY HAVE PPI FORUMS NOT BEEN MORE SUCCESSFUL

What exactly was the brief from government? Was this just a window dressing exercise? If so it was an astonishing waste of the best part of £90 million of public money spent on a badly thought out administrative design. Far too many civil servants were employed to support and facilitate voluntary workers, but in many cases they treated these people with contempt, patronised them, refused them cooperation, made official complaints which took months to resolve, and generally tried to tie up Forum members in their red tape and lengthy time wasting procedures.

Why were there two groups of civil servants—those who worked for the Commission for Patient and Public Involvement, and the FSOs—Forum Support Organisations, when one properly organised group could have done whatever might have been required. . .This has wasted more time and resources unnecessarily than anything else to do with PPIFs. Selective pieces of information would be sent from CPPIH directly, but the rest sent on to FSOs and then on again to Forum members—wasting time and postage.

Right at the beginning of the UCLH PPI Forum, exactly three years ago, we asked for leaflets to be distributed throughout local libraries, doctors surgeries, all community centres, (including those of other nationalities). This has never been done. This has deprived the public of knowing of the Forums' existence, certainly in Camden with a large mixed community. When Meetings in Public have been held, Forum members have had to distribute leaflets/posters to these places, because the public are unaware of the work we do, attendances have been poor.

The UCLH PPI Forum has had additional problems achieving cooperation from the Trust. This status was not yet confirmed when we began working with them, but they were already planning their own Members' Council, which they feel more comfortable with, and it has been a huge uphill struggle getting any information of any hospital initiatives, let alone invitations to be involved, other than the barest minimum. One has even been given only 24 hours notice to attend PEAT (Patient Environment Action Team) inspections, which are certainly planned by the Trust team some weeks/months in advance. It was made very plain from the beginning that we were considered completely unnecessary to the well being of patients/public in relation to the seven hospitals in the UBLH Trust.

In spite of this, we have made every effort not to tread on toes, but to learn everything possible, and to be helpful to staff as well as the patients. We have sent copies of reports to the Trust, indeed we have done a great deal of work for them, which was not undertaken by their Members’ Council.

We are indeed a “critical friend”, in a way that no other independent body exists, and should be allowed to make independent inspections as before under any new system/initiative chosen.
We should also be allowed to see budgets and accounts. According to the National Audit Office this is correct but CPPIH have continued to refuse requests.

Transparency does not operate, the tax paying public deserves better, but if we PPIFs are not consulted, (and not just those Forum members loyal first to the civil servants) no system will be effective, which can only reflect badly on the government who put it in place.

Veronica Brinton
University College London Hospital Foundation Trust PPI Forum
4 January 2007

Evidence submitted by Wandsworth Primary Care PPI Forum (PPI 69)

1. What is the purpose of patient and public involvement?

To give patients and public a voice in the design, development, provision and quality of health and social care services to the local population.

2. What form of Patient and Public Involvement is desirable, practical and offers good value for money?

The model should be independent of the NHS, Health Trusts and Local Authorities. The members should comprise a cross section of the local community, based on existing PPIF members, patient participation groups, local stakeholders and community groups.

3. Why are existing systems for Patient and Public Involvement being reformed after only three years?

Yes, why?

4. How should LINks be designed?

4.1 Remit and level of independence

— To monitor and review services provided by Healthcare Trusts (Hospital and Primary Care) and other commissioners (e.g., Practice Based Commissioning) and Social services.
— To collate views of patient, users and carers about the services provided and report to and make recommendations to the appropriate body.
— To enter and inspect premises providing services and report on conditions found.
— To encourage public involvement in PCTs, Hospital Trusts and Social Services’ consultations and policies.
— To encourage all LINk members to be involved at every level in the organisations providing health and social care to influence strategy and strategic thinking and to take part in decisions relating to the commissioning of services.

The model should be independent of the NHS, Health Trusts and Local Authorities.

4.2 Membership and appointments

The basic model contract should be for a host organisation to administer a LINk, not to “run it” which should be done by members.

To attract members, building on existing activity in the voluntary and community sector needs to be done locally based to the extent possible on existing PPIF membership.

The following will be required:
— The independent powers of the LINk need to be made very clear, as is now done for the PPIF.
— Develop a clear organisational structure for user involvement, building on lessons learnt with previous two types of organisations.
— Members of the LINk should appoint a Chairperson as leader.
— Define initial training and briefing needs of user and lay representatives.
— Define longer term development and support needs for user participants and support teams.
— Account needs to be taken of the lessons learnt in recruiting for the last two types of patient organisations. We can provide examples.
Members should be able to claim attendance allowance when representing LINks in a meeting, as per recommendations in DoH January 2006 report on best practice.

4.3 Funding and Support

- The basic model contract should be for the host organisation to administer a LINk.
- It should provide adequate, competent and experienced administrative support for the LINk.
- Ideally it should have knowledge of the NHS and Social Care and be familiar with the local area and service provision.
- It must be able to support LINks to research and gather information, analyse data, write reports and present information. It must be independent of the local authority.

Funding of the LINk should be very clear and managed by the local LINk members. The budget allocated to the Local Authority by the DoH for the LINK activity should be ring fenced to ensure it is wholly available to LINk members and not used for any other purpose. The amount of funding should be based on the size of the population, the geography and other criteria.

4.4 Statutory powers

Link needs to be an independent body legally set up with powers of the PPIF as at present. LINk should retain the existing inspection powers of PPIF but the objectives of such inspections must be spelled out more clearly.

4.5 Relations with local health Trusts

Links should build on the positive and constructive relationships which have been developed by the PPIF. Much good work has been achieved and care must be exercised that it is not dissipated in the changeover.

5. How should LINks relate to and avoid overlap with

5.1 Local Authority structures including Overview and Scrutiny Committees

LINks should retain the statutory powers held by PPI Fora. They should remain independent of OSCs but should actively cultivate a complementary and productive relationship with OSCs. LINks should have the power to refer issues to OSCs for action.

5.2 Inspectorates including the Healthcare Commission

LINks should develop good working relationship with these bodies to ensure there is not unnecessary overlap with the regulators inspections but that their activities are complementary.

5.3 Formal and informal complaints procedures

Whatever the format, it is essential that responses to complaints should be written in simple, plain non-ambiguous, non-technical language.

6. Subjects not addressed

- Areas of Focus.
- National Coordination.
- Foundation Trust Boards and Member Councils.
- Wider Public consultation.

Bridie Tobin
Chair, Wandsworth Primary Care PPI Forum

Evidence submitted by Warwickshire PPI Forum (PPI 5)

The PPI Forum has asked me to write to you on their behalf expressing their concerns at the proposed arrangements for Patient and Public Involvement in health when the new LINks take over from the PPI Forums (under the “Stronger Local Voice” Proposals).
1. **Statutory Powers**

1.1 One of the Forums’ major strengths is their right to monitor NHS and NHS funded services, which includes the valuable right to enter and carry out inspections. This right of monitoring and inspection has been used to great effect in Coventry and Warwickshire and without this statutory right, any future organisation would be entirely dependant on whatever information the relevant NHS body cared to pass on. Whilst some concession has been made on this point, we await further clarification.

2. **Membership/Areas of Focus**

2.1 We are also concerned at the structure of the proposed LINks. There is a very real risk that it will be so widespread in its membership that it will become little more than an ineffectual talking shop. At present, Forums develop a yearly workplan which focuses on a few issues important to local patients based on evidence gleaned from our community engagement programme, but this would be impossible with a much larger group with many vested interests.

2.2 Another area of concern is that Children’s services are not covered under the proposed arrangements. If the LINks are supposed to cover a much wider range of health and social services, then we feel that this most important area should also be included.

3. **Funding and Support**

3.1 Professional and effective support arrangements are essential to the success of PPI Forums as they would be to any future organisation, and the Forums urge that sufficient financial support be available from the DoH to enable this.

3.2 We feel it is important that any such funding granted to Local Authorities is “ring fenced” to ensure is used solely for the running and support of LINks and is not diverted to other purposes.

*David Gee*
Chair, Warwickshire PPI Forum—South Warwickshire Locality Committee

19 December 2006

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**Evidence submitted by Westminster PCT PPI Forum (PPI 102)**

1. **What is the purpose of PPI?**

The purpose of PPI is to ensure that the views and experience of patients and the public inform and influence decisions by NHS commissioners/providers about the planning, delivery and monitoring of healthcare provision.

3. **Why are existing systems for PPI being reformed after only three years?**

One of the reasons given is the need to widen the membership of PPI organisations. However, this could have been done under the existing system by having recruitment for new/expanded PPIF membership reach out to representatives from voluntary and community organisations. Another reason given is that the increasing emphasis on commissioning within the NHS requires that PPI organisations be established for a geographical commissioning area rather than for a specific organisation. That is probably valid, although it should be noted that PPIFs for PCTs (such as ours) in effect already serve a commissioning jurisdiction.

A third reason cited is the inconsistency in effectiveness of PPIFs across the country. However, “effectiveness” will not automatically be improved simply by changing the structure of the PPI organisation. So in the formation of LINks, there should be emphasis not only on identifying “good practice” among existing PPIFs, but also on understanding the reasons for sub-standard performance so that can be avoided in LINks. The comments of the Expert Panel to the DH (12/5/06) that “PPI has suffered badly from . . . stop-start policy” should be heeded so that LINks do in fact build on the strengths of the existing PPIF system in holding commissioning organisations to account, where such experience exists.

4. **How should LINks be designed, including**

   (a) Remit and level of independence. The remit should focus on PPI in commissioning, with the understanding that good commissioning encompasses consultation with users on planning services, performance monitoring of providers and assessing patient experience with services. We think that the proposal in the 11/12/06 DH feedback on the Stronger Local Voice consultation, to have working groups within a LINk to address the various parts of its remit—commissioning, provider monitoring, specialist providers—is good.
We think it is essential that LINks be independent of the DH, Local Authority, NHS, Host and any other organisations.

(b) Membership and appointments. The DH documents talk about both “organisation and individual” members of LINks, but it is not clear how these different categories of membership might work. There is also nice-sounding language about LINks being not just a group of people but “networks” and about how membership decisions will be up to individual LINks instead of being prescribed centrally. But we think there is still a big piece of work to be done on how the individual/organisational membership structure of LINks might be operationalised. We think that this needs to be addressed before LINks are unleashed to tackle this on their own. One way of doing this is to ensure that the early adopter sites go through a period of being a “shadow” LINk (as suggested in Annex A of 11 December 2006 DH document) and develop various models for membership. We reiterate our comments on the Stronger Local Voice consultation that each LINk go through a “shadow” stage, with perhaps a committee of two PPIF members who want to transfer to the LINk and the Host being responsible for selecting initial LINk members. Questions of member suitability, time availability, expertise, experience and people mix also need to be considered. In addition, we recommend that consideration be given to paying volunteer members of LINks a stipend as a way of attracting membership, particularly among younger people.

We are pleased that the Minister’s covering letter to the 11/12/06 DH document explicitly states that “it is not our intention to abolish patients’ forums . . . until LINks can be established.” We think this is essential. However, doubt is cast on this assurance by the worrying language in para 1.10 of the DH document that refers to “minimising the gap” between systems.

(c) Funding and support. Funding should not be any less than at present and should be ring-fenced. We are pleased to see in 11 December 2006 DH document that detailed specifications for the qualifications and level of support to be offered by Host organisations are being developed. We note that one reason often cited for poor PPIF performance has been the poor performance of their FSOs. We think it cannot be assumed that LAs will automatically be more effective than CPPIH in selecting effective Hosts, even in view of their greater local knowledge. Therefore, this procurement process needs very careful management and guidance. We think it is essential that the LINk participate in interview panels for new Host staff and in formal assessment of Host performance.

(e) Statutory powers. We think that these powers should not be less than for PPIFs and are pleased to see in 11 December 2006 DH document that it has been decided to give LINks the right of access to monitor and inspect services. LINks should also have the power that PPIFs have to hold NHS organisations to account by commenting on their declarations of compliance with HCC standards as part of the Annual Health Check.

(f) Relations with local health Trusts. Forming a good working relationship with local health Trusts is desirable to permit joint working to improve PPI and the quality of health services. LINk members should participate, as PPIF members do now, as “critical friends” on Trust Boards, committees and working groups.

5. How should LINks relate to and avoid overlap with

(a) LA structures including OSCs. LINk members should not be members of OSCs but should be given the opportunity to contribute to OSC investigations. LINks should retain the same ability to refer issues to OSCs that PPIFs now have. In this regard, we are concerned that section 157 of the Local Government and Public Involvement in Health Bill provides for referral of social care matters to the OSC but not healthcare matters.

(b) Inspectorates including the HCC. LINks should be given the opportunity to contribute to HCC and other inspections.

6. Wider public consultation (including section 11). The requirements now placed on Trusts to consult with patients and the public on planning and proposing changes to healthcare services should remain. This should include the opportunity for LINks to provide a formal response to such consultations. LINks should build on and strengthen existing PPIF work to hold NHS organisations to account for conducting —and acting on—appropriate consultations under section 11. While we are pleased to see inclusion in the Local Government and Public Involvement in Health Bill of section 163 regarding the duty of NHS Trusts to consult about planning/changing health services, we are concerned that the language refers only to “significant” changes, thus potentially diluting the effect of the current section 11 duty.

Tera Younger
Co-Chair, PPI Forum for Westminster PCT

Brigitta Lock
Co-Chair, PPI Forum for Westminster PCT

10 January 2007
Evidence submitted by West Sussex PPI Forum Chairs (PPI 67)

1. Does Patient & Public Involvement (PPI) make a worthwhile contribution to the NHS?

In principle, both PPI Forums and the CHCs have provided a continuous monitoring of NHS activity. Providing that it is independent and constructive, monitoring of Trust activity allows members of the public to examine changes to services (sometimes small, but significant to a group of patients) and to identify weaknesses revealed in Board reports. This monitoring, including the ability to question directly those responsible for the service, has always been supported by the ability to inspect NHS facilities.

An experienced PPI Forum member has been able to act as a patient advocate, particularly in areas of patient care, rather than clinical treatment.

A particular weakness has been the inability to directly monitor GPs, who are in the main contracted to the NHS, but guard their independence vigorously. Under the existing system they can only be questioned through their PCT or inspected by QOF inspection. However even this ability may be lost under LINks.

There are dangers of duplication, which may well place undue pressure on NHS staff. The Trusts’ own PPI activity and possibly that of HOHC do, at times, cover the same ground, but lack the independence that both the CHC and PPI Forum system have enjoyed.

2. Do PPI Forums represent the population and would LINks be better?

The answer to both these questions is no. Inevitably the majority of members will need to have time available and the ability to understand a complex organisation. LINks may be paternalist and have a membership from those with the widest possible range of backgrounds. This has been a problem and weakness of both CHCs and PPI Forums, but there is no reason to believe that LINks would change this and there is a greater risk of potential bias.

There has never been a rush to join either the PPI Forums or CHCs and it is difficult to see how LINks will attract a greater membership. Younger people are particularly difficult to enrol because most meetings and research work has to be done during normal working hours.

3. Can the relationship with the voluntary sector be strengthened?

The answer to that is that it should be. However, the CHCs were established to include direct membership of voluntary organisations and in West Sussex at least, had difficulty in recruiting people with sufficient time and interest. Our PPI Forums have endeavoured to gain support and input from voluntary organisations, but generally unsuccessfully. Voluntary organisations and their active members are concerned with their “cause”. Trusts do consult and include them in specific subjects but there is no evidence to suggest that their members feel isolated from the NHS or would wish to broaden their contribution to it. They should clearly be consulted when particular services are under review eg Diabetes, Cardiac, Geriatric care etc.

4. Is the Healthcare Commission a replacement for the present PPI system?

No. It has a relatively small staff (about five people in our area), who examine the performance of Trusts on a broad performance basis with occasional visits or discussions. If they do inspect, it is a snapshot sample or in response to a particularly serious incident identified by the media or even a PPI Forum.

PPI Forums provide a continuous review of services and, in particular, can identify minor problems of a very local nature. The quality of this depends on the range of contacts that PPI Forum members have in their community. However PPI Forums have the same basic objective as the Healthcare Commission and should be more closely associated with it. In particular, PPI Forums should have the right to refer problems to it, when these have not been resolved or answered by the Trusts. This is more practical than the right to refer to the Secretary of State, which should be retained as a last resort.

5. Co-terminosity with local authorities and social service providers

In our case this has two fundamental weaknesses. West Sussex is quite large, both in area and population (approx. 1 million), so that it is impossible to regard any patient organisation as local. However, the critical care hospitals in Brighton, Portsmouth and Redhill are, in fact, in neighbouring local authority areas while the Princess Royal in Haywards Heath is the responsibility of Brighton and Sussex University Hospitals Trust. (The other acute Trusts are Worthing & Southlands, Royal West Sussex in Chichester and the Queen Victoria Hospital Foundation Trust in East Grinstead).

The Sussex Partnership (for mental health, learning difficulties and substance misuse) in fact covers three social service providers, East Sussex, West Sussex and Brighton & Hove. Clearly no one patient group can cover this ill-defined area, so it would naturally be organised into specific areas of responsibility. These are PPI Forums, which are about to be destroyed, even though they have developed considerable experience and strong links with the West Sussex HOHC and Healthcare Commission.
6. Are LINks practical and credible?

The membership and recruitment process seems nebulous, but it appears that there will be a core membership with the ability to summon into membership others who might be interested in a particular subject. LINks will not be attached to any NHS Trusts but will still have powers to inspect and presumably monitor all the Trusts within the area and those outside it who serve the population. The idea of the wider membership is presumably (and understandably) to give LINks a more democratic basis, although this is surely provided by the local authority HOSC. The range of tasks, which appears to include social services, seems far too large a burden to place on volunteers, especially those who take on responsibility. Some structure will therefore need to be created to link with particular activities eg mental health.

7. Administration of LINks

This is to be provided by a HOSEC body, possibly part of a voluntary organisation appointed by the HOSEC. Budgets will apparently be limited overall to that provided for the CPPIH, although it will not be ring-fenced. It is difficult to know whether this is practical, however there is a need to establish connections with a wide membership, to train them and to keep them informed. Our PPI Forums in West Sussex have, until very recently, been supported by a voluntary organisation (contracted by the CPPIH), over which the members had no control, either in terms of finance or the use of staff resources.

The CHCs had a dedicated staff, with a clear budget, the whole being managed by a small group of members responsible to the Council. This was a more satisfactory and responsible arrangement. Using voluntary organisations with limited expertise in the activities of the NHS is paying lip service to voluntary organisations, which in practice is not justified.

8. Patient Involvement in Primary Care

There is a danger with LINks that attention will be focused on acute care in hospitals as this tends to draw the attention of both the media and the public. However, as the Government frequently emphasises, the focus should be on Primary Care and Care in the Community. GPs are mostly independent of the NHS, yet contracted by it. PPI Forums have some influence through the related PCT and should have representation on the GP Commissioning Groups which, it is assumed, will gradually assume responsibility for community hospitals and nursing services. There is no apparent provision in the LINks scheme to have even this level of influence.

Some GPs have their own patient groups, but some of these are more like supporters’ groups than constructive critics. GP practices are also subject to QOF assessments but the detailed results are confidential. Mental health services, likewise, do not attract the same attention as hospitals yet need to be carefully monitored, particularly as it is an area too often disregarded.

9. Recommendations

(a) Structure of LINks

Can we find a better name? The structure needs to be better defined, in particular the exact nature of its relationships with the local authority as the social services provider and with the NHS Trusts. The problem in a large county area is different to that in urban areas. In order to engage the public some local organisation is essential, reporting to the main LINKS. In our area, the problems in Crawley, Worthing and East Grinstead will vary.

(These questions are raised in pp 13–16 of the Government response to ‘A stronger local voice’ published in December 2006.)

(b) Services should be provided by a dedicated staff appointed by the local HOSEC. The management should be the Executive Manager, HOSEC and Healthcare Commission representatives and three members of the LINks within the HOSEC area.

(c) Members should be recruited locally and be appointed by a group of at least three, including the Manager and a representative of the appropriate PPI Forum.

(d) Training should be organised by the Healthcare Commission and should also be available to HOSEC members.

A reasonable amount of finance should be identified to publicise the existence and activities of the LINks and to establish better connections with the voluntary organisations. The aims, so far described, suggest a need for significant communication expenditure eg publication & distribution of newsletters etc.

Members of LINks should be nominated to serve on Commissioning Groups, Primary Care Trusts and all the NHS or Foundation Trusts, which should have a responsibility to advise the LINK of any service changes. Monitoring is a two-way activity—an informed membership with wide community contacts. (see pp 26/7 of DoH response.)
The Government response paper describes a very ambitious set of proposals, which will take time to implement and develop. It should be accepted that no significant change will be made for at least five years to give the plan a chance of success.

Stuart Henderson  
Chair, West Sussex PCT Independent PPI Forum

Robin Kemp  
Chair, Sussex Partnership PPI Forum

Anthony Preston  
Chair, St Richards (Royal West Sussex) PPI Forum

Derek Richardson  
Chair, Woking and Southlands Hospitals PPI Forum

January 2007

Evidence submitted by Which? (PPI 106)

Introduction

1. Which? is an independent, not-for-profit consumer organisation with around 700,000 members. Based in the UK, it is the largest consumer organisation in Europe. Entirely independent of government and industry, we actively campaign on behalf of consumers and are funded through the sale of our Which? range of consumer magazines and books. 2007 marks our 50th anniversary.

2. Which? has a long-standing interest in a wide range of health issues, and through our work we seek to make individuals as powerful as the organisations they have to deal with in their daily lives. Consumer influence and representation is one of the core consumer principles and the subject of patient and public involvement in decisions about health and social services runs through our work. In considering our response to the Committee, we have drawn on research and analysis across a number of health issues and we have focused on the principles and aspirations we hold for patient and public involvement.

Summary of Which? Views

3. Which? welcomes this timely inquiry by the Committee. Public and patient involvement should be at the heart of the NHS and the decisions it takes in commissioning and providing services, particularly in today’s “patient-centred NHS”. However, recent reviews and reforms lead us to question the Government’s commitment to involvement and engagement of this nature.

4. In our view, listening and acting on the views of patients and the public should be a fundamental part of the core business of the NHS. However, we are often left with the feeling that consulting and involving patients and the public is tacked onto deliberations because of statutory duty, or worse not included at all. For example, decisions about the revised GP contracts were made without any representation of consumers’ interests despite the significant impact these decisions had on the choices open to individuals about access to out-of-hours care.

5. We will address in detail some of the questions raised by the Committee. However, we would like to highlight three key points:

(a) We strongly believe that patient and public involvement in the NHS should be integrated across all NHS care, not limited to particular structures and opportunities. It should be a feature of all decisions, from 1:1 consultations between a patient and health professional, to national policy-making by the Department of Health.

(b) The success of patient and public involvement in health should be judged on the spirit and culture of openness in the NHS and a willingness to hear users’ views, not solely on structures and bodies established to meet statutory consultation requirements.

(c) The frequent review and reform of patient and public involvement opportunities leaves consumers with a sense that Government commitment to the ethos of wide consultation is wavering.

What is the purpose of patient and public involvement?

6. The purpose of patient and public involvement in health is to deliver a health service that meets the needs of people using the NHS. Understanding the views, experiences and needs of patient and publics helps to inform the development of services so that they better meet the needs of its “customers”. For example, we believe it has a key role in identifying choices for patients and the public under the Government’s policy of Patient Choice. Individual patient choice alone cannot be relied upon to direct the provision of community and regional services; patient and public involvement is necessary to ensure the NHS meets people’s needs.
7. Which? is concerned about the strict definition of patient and public involvement in health that has been adopted as common use. The debate so far has focused heavily on getting the right structures and organisations in place. But of equal importance is the emphasis on a spirit and culture of openness and listening that is also needed throughout the NHS.

What form of patient and public involvement is desirable, practical and offers good value for money?

8. Which? believes we need to be bold, creative and genuine and embed the voice of the patient and publics at the heart of the NHS as a clear way to improve the delivery of healthcare. It requires all those involved in delivering healthcare to be willing to actively listen to their patients and the public and to be willing to take action on the issues that really matter to people.

9. In addition to the formal arrangements for “voice”, both health trusts and local authorities have duties to inform and consult the local community. However, significant variations exist in how they discharge these duties. If “voice” is to really act as a lever for change in the NHS, it must become central to everything that commissioners and providers do. They must also approach “voice” in more creative ways, seeking feedback and involvement at every stage and in different ways, particularly seeking out the views of less vocal sections of the community.

10. Outlining a form of patient and public involvement that is desirable, practical and that offers value for money will inevitably depend on one’s perspective and priorities. Which? believes the key characteristics that patient and public involvement must display are:

(a) An extended reach for patient and public involvement, that seeks to include more of the population. According to Which? research in 2005, only one per cent of the population has ever been active in patient and public involvement forums. Yet, the public want to be heard, as nearly two-thirds of people interviewed in our survey said the public were not involved enough in local and national health care decisions.

(b) The ability for every patient to feel they can give feedback. A Healthcare Commission survey conducted in 2005 found that only 6% of in-patients in England were asked for their views about the quality of their care while in hospital.

(c) A clear and easy to use complaints procedure that ensures complaints are responded to effectively. Formal complaints can be valuable in highlighting improvements that are needed, but most people do not complain. Often people want an apology or an acknowledgement that things didn’t go to plan. Which? also believes the NHS needs to be able to cope with more serious concerns. We believe patients need help when things go wrong to enable them to raise their concerns. Many patients are afraid to complain, fearing their care may be jeopardised as a result. This must change. Making a complaint about health care can be very stressful for patients and their families. At a time when they should be recovering, patients are faced with alien processes and unwelcoming procedures, which more often than not deter them from making a complaint.

(d) Investment and resources to facilitate success and deliver value for money. These funds would support the structures and tools needed to seek the views of patients and the public; provide resources to reconfigure services so they better meet patients’ needs; and train and develop staff who are so crucial to patients’ experiences of the NHS.

(e) A “willing to listen” culture throughout the NHS that will take on board comments, suggestions and complaints from the users of its services, with the aim of delivering better care. We believe structural and process changes may help to achieve some improvements but fundamentally until the doctor, the nurse, the PCT, the Secretary of State, see it as their job to ensure the patient is put first, then the radical shift in how the NHS provides its service will not happen. The patient must be put first.

11. Our concern is that frequent national reviews and reforms of patient and public involvement structures is indicative of the low value placed on them by Government. We believe formal patient and public involvement structures need a period of stability to develop a sustainable capacity in the community. Fundamentally, the efforts to develop “desirable” and “practical” involvement opportunities are restricted by a lack of sufficient resources both now and in the future.

12. We firmly believe that there should be a national standard of involvement and engagement of patient and publics in the NHS. The appointment of a Director for Patients and the Public by the Department of Health is only a recent one, whereas for years it has employed a Chief Medical Officer, a Chief Nursing Officer and a Chief Pharmaceutical Officer all of whom have considerable influence over policy and decision-making processes. The abolition of the Commission for Patient and Public Involvement in Health and the

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88 Unpublished Patient and Public Involvement Omnibus 2005. Questions were placed on a face-to-face omnibus. 771 adults in England aged 16+ were interviewed.
Ev 280  Health Committee: Evidence

absence of a replacement body leaves a vacuum in the representation and involvement of patients and the public in national health decision making. It also means that it is not easy to build up a national picture of how policies are operating locally. This is a grave cause for concern.

Why are existing systems for patient and public involvement being reformed after only three years?

13. This is a question for Government to answer. The rapid reform is puzzling. In the light of Primary Care Trust reconfiguration, it is perhaps understandable that some changes to patient and public involvement would be necessary. However, the radical reform outlined in “A stronger local voice”, coupled with the long heralded abolition of the Commission for Patient and Public Involvement in Health, leads us to question the Government’s commitment to meaningful and sustained patient and public scrutiny, inspection and involvement in the NHS.

14. Whatever rationale is offered, it is clear is that changing the formal arrangements for patient and public involvement, the second within four years, creates a climate of uncertainty that has left patient and public involvement at a local level in a very fragile state.

How should LINks be designed, and how should LINks relate to and avoid overlap with other bodies?

15. LINks will bring together involvement arrangements for health and social care, involve community groups, not just health groups, and be able to take a broad view of health. While LINks offer some opportunities, Which? is not confident that they will have sufficient power or resources to play a major part in facilitating the changes required to achieve the vision of a patient-centred NHS. LINks are likely to be under-resourced to fulfil their responsibilities to health and social care, and although local authorities will receive a targeted specific grant for their support, it is not ring-fenced money. There is also considerable uncertainty about they will operate (including their membership, recruitment and governance structures) and accountability arrangements.

16. The present funding arrangements for NHS services means local scrutiny is appropriate. But replacing the current scrutiny of a trust’s activity with oversight and involvement on a much wider geographical basis seems a retrograde step, lessening the opportunity for meaningful patient and public involvement in health according to the principles we have outlined here. The danger is less one of overlap with other bodies, rather that the huge remit that LINks will work to leaving some issues and services neglected.

17. We hope this inquiry can offer further guidance on the issue of concern about the operation, membership, and governance of LINks. From our perspective, the proposals have placed considerable responsibility on these loosely-defined organisations, without essential guidance, expecting them to fulfil a range of functions and duties that have historically proved tricky to run. As we move forward and patient and public involvement develops, it is essential that we build on what has worked well under earlier arrangements, and do all we can to ensure that previous experience is not wasted.

Kate Webb
Which?
10 January 2007

Evidence submitted by Whipps Cross University Hospital NHS Trust (PPI 116)

Purpose of Patient and Public Involvement (PPI)

— To facilitate achieving the vision in the NHS Plan, particularly that set out in Chapter 10 para. 10.35 “...reforms which will bring patients and citizens into decision-making at every level... involvement of citizens in redesigning the health service from the patient’s point of view.”

Desirable, Practical Format Offering Good Value for Money

— A mixture of approaches would best meet the criteria above.
— At Whipps Cross we have a Patients’ Panel comprising local people from a range of organisations eg Sickle Cell, Diabetes UK, Waltham Forest Asian Seniors Club plus a number of interested members of the public who may be patients, carers, ex-complainants. The Panel members have been invaluable in giving feedback, editing patient information, training staff and working with staff on project groups.
— We also link with about 45 local organisations building relationships and exchanging information about issues from patients, carers and visitors. They have been instrumental in helping us improve services eg helping us design and pilot a Carers Policy to heighten awareness of staff about the important role carers have in our patients' well-being.

— The PPI structure within NHS Trusts should facilitate:
  — Patients being involved in decisions about their own care.
  — Opportunities to shape, comment on, and monitor service provision.
  — Equal access to services.

Why Reform after three years?

— Good question. The reforms should strengthen the good practices established and improve the weak ones.

— The new PPI structures should be piloted, evaluated and then given time to settle down before any further changes are made.

LINKs Design

Membership/Appointments

— LINKs should not be set up in haste; the process should be properly managed.

— Each should be a small group formally appointed and accountable to the local population for representing their interests.

— The members should be able to provide evidence of achievements—this does not have to be at high level but it should not just be membership of a number of committees.

— Members should be able to demonstrate how they would involve local people in decisions about local services and how they would publicise the LINKs' work.

— They should understand that they are accountable for outcomes (or lack of them).

— Members should be independent of service providers particularly as the trend is to encourage the voluntary sector to provide services.

— It may be necessary to pay members a nominal sum in return for a contract similar to that applied to Non-Executive Directors of health trusts.

Funding and Support

— Funding should be ring-fenced so that it cannot be absorbed into general local authority services.

— Resources should be structured, realistic and include dedicated good quality administrative staff.

Focus Areas

— Engagement with the local population should be a high priority so that residents are aware they have this mechanism of influencing health and social services.

— Priorities should link to the Public Health priorities and those agreed by the Overview and Scrutiny Committee.

— The LINKs should publicise their priorities widely and give local people the opportunity to influence them.

Statutory Powers

— These should be clearly set out and include the presentation of an annual report to the local health organisations and local authority. Those organisations should be required to respond as appropriate.

— Should include visiting rights, properly managed, with clear parameters.

— Should include the right to refer issues to the Secretary of State.

— Should cover health and social care.

— LINKs should be co-terminous with PCTs.

— Consideration should be given to a requirement for employers to give time off work for members—similar to that for magistrates.
Relationship with Local Trusts

— Should be businesslike and act as a critical friend.
— Work collaboratively but be independent.

National Co-ordination

— Necessary to give the LINKs a national voice—to give them “teeth”—and to give support to the local LINKs.

Shona Brown
Director of Nursing and Quality, Whipps Cross University Hospital NHS Trust

10 January 2007

Evidence submitted by Winchester & Eastleigh Healthcare Trust PPI Forum (PPI 44)

How should LINKs be Designed

Remit and level of independence

Remit

— Reflect local concerns and help shape local services.
— LINKs wishing to work with and be associated with hospitals should be able to do so.
— LINKS associated with hospitals should monitor the services provided within the hospital but keep in touch and work with pre and post hospital services provided by NHS and Local Authorities.
— Work jointly with other PPI LINKs eg PCT based LINKs.
— Engage with the public at every opportunity—concentrating on issues relating to the hospital but passing on other issues to appropriate LINKS.

Independence

— Complete independence of any statutory body.
— Support organisations should be independent too.

Membership and Appointment

Membership—anyone

— With an interest in improving local health services and with time to spare.
— Willing to deal with a fair amount of paperwork—reading documents, helping to produce reports, etc.
— Willing to meet and talk to groups and people in the community (engaging with the public).

Appointment

— Should be undertaken by an independent body that really understands the role of LINKs—what it means to be a member and what is expected.
— Appointees should be able to assess and preclude inappropriate applicants, eg, those with prejudices.
— Appointments should be made simple and the process carried out speedily and efficiently.

Funding and Support

Funding

— From central government.
— Sufficient.
Support
— Support as provided by a good FSO who knows the patch and understands the role of the LINKs.

Areas of Focus
— Hospital based LINKs should focus on the needs to maintain a good service for its patients.
— They also need to understand the needs of the local health economy and the Hospital’s relationship to the whole. Therefore the Focus may well need to shift outside the Trust—eg.
— LINKs would still need to focus on the views of its local community.

Statutory Powers
— Are essential—without them LINKs could be ignored.

Relations with local Health Trusts
— Statutory powers will help to strengthen the links with local Health Trusts.
— Hospital based LINKs would need to develop a working relationship with their Trust or continue with the relationship previously developed by the PPI Forum.

National Co-ordination is an absolute necessity
— Maybe undertaken by Healthcare Commission.

How should LINKS Relate to and Avoid Overlap with

LA structures and OSCs
— Communicate through support team.
— Important to keep a good relationship with OSC—two way traffic needed.

Foundation Trust Boards and Member Councils
It is questionable whether there would be a role for Hospital based LINK when its Hospital becomes a Foundation Trust.

Inspectorates including Healthcare Commission
Assume Healthcare Commission would be the major body monitoring the performance of LINKs.

Shirley Kenneally
Winchester & Eastleigh Healthcare Trust PPI Forum
January 2007

Evidence submitted by Worcestershire County Council Health Overview and Scrutiny Committee (PPI 115)

Executive Summary
The following is a submission from the Health Overview and Scrutiny Committee of Worcestershire County Council.

The key issues that are facing patient and public involvement (PPI) are identified as being the degree of commitment to PPI within all levels of the structure, from Government through to primary care providers and the impact of financial difficulties upon genuine PPI. A number of local experiences of these issues are outlined.

Finally, the submission offers a number of suggestions for the improvement of patient and public involvement within the NHS.
Introduction

1. Worcestershire County Council’s Health Overview and Scrutiny Committee (HOSC) was formed in 2003 and comprises seven County Councillors and six District Councillors, one from each District in the County.

2. Since its formation, the HOSC has been involved in the planning of, and been respondent to, a number of consultation exercises conducted by local NHS bodies since the Health and Social Care Act 2001. This has afforded Councillors and Officers the opportunity to experience a variety of different approaches taken by NHS bodies to patient and public involvement in health.

3. This experience informs the following submission, which focuses on the Health Committee’s questions regarding:
   - The purpose of PPI—which we have interpreted to mean as including wider public consultation under Section 11 and Section 7 of the Health and Social Care Act 2001.
   - When and how we feel PPI should be carried out.
   - Why is it being reformed—to assist in this we have described some of our experiences on how PPI has been working in Worcestershire.

4. We conclude with our views on the process and some suggested recommendations for improvement.

Purpose of PPI

5. PPI is a necessary process to ensure patient-centred care, and the involvement of Health Overview and Scrutiny Committees helps to reduce the democratic deficit in the NHS. PPI must be seen to have clearly influenced the final decisions regarding service changes and reconfigurations. However, it is essential that such involvement has been an integral part of the development of proposals. Members recognise that it is naive to expect that all decisions taken will be supported by the patient and publics, but it is still important for patients to have a say—how else can the NHS understand patients’ experiences?

When and How Should It be Carried Out?

6. We do not attempt to set out a blueprint for good practice in PPI. However, there are several points which we feel should be borne in mind when addressing this question.

7. Local NHS bodies should be framing all changes and reconfigurations, both expansions and cuts, within an ethos where PPI fundamentally underpins the organisation’s decisions.

8. If the PPI strategy is to be trusted by the patient and publics it hopes to involve, then it must apply at all levels within the NHS from the Department of Health through to primary care providers.

9. There is a difficult balance to tread between how early to involve the patient and publics, and indeed Health OSCs. It is important that those consulted feel they have a genuine ability to influence decisions, but Members recognise that very early consultation could raise fears about the future of services, which may subsequently amount to nothing. It is suggested that this problem will inevitably remain, but that perseverance with PPI and the ongoing education of the public in the PPI strategy and the importance of a strategic perspective will go some way to addressing concerns.

Impact of NHS deficits on consultation

10. A significant concern that arose during 2006 was the impact that the need to make financial savings seemed to have on PPI. Our examples in the next section show that although the vast majority of the proposed service changes would have a direct impact on patients and the public, their rationale appeared to be based only on the need to make financial savings rather than having emerged through PPI. Members of the HOSC recognise that it is important for the NHS to address financial deficits. However, there appears to be no leeway for trusts to ensure proper PPI whilst considering how to reduce deficits. The result is a series of consultations where proposed changes are dictated purely by financial needs.

11. Although national and local rhetoric is that service changes and reconfigurations aim to improve services, it is noteworthy that more often than not, significant financial savings accrue from most proposals. Whilst there would be concern if proposed changes were not cost-effective, we consider that the effect of an ongoing emphasis on saving money within the NHS will have a negative impact on the public’s perceptions of service changes and reconfigurations.

12. If the Government is truly committed to PPI, priority should be given to getting the basis for change right rather than simply remaining focused on the financial balance sheet, ie service changes and reconfigurations being led by local need and patient and public input rather than financial crises.
Why is it being Reformed: How has it been Working?

13. Worcestershire HOSC welcomes the efforts local NHS trusts have made to keep us informed and involved during what has been a particularly difficult year for them. Generally NHS staff have been willing to attend and provide information when requested. However the process has not been painless; at the risk of painting an unbalanced picture we believe the following examples will be of use to the Committee in its consideration of the PPI process.

14. In mid-2006 a series of proposed changes to services was put forward by the then three primary care trusts (a single PCT was formed 1 October 2006). It was made clear that the aim behind the proposals was principally to address financial deficits. A series of 60 service changes were proposed and were brought to the HOSC to discuss whether formal consultation under Section 7 was required. It was clear to us that although the vast majority of the changes would have a direct impact on patients and the public, they were based only on the need to make financial savings rather than having emerged through PPI.

15. In the acute setting, the Committee may be aware following some publicity, that changes were being proposed to chaplaincy services in the County’s three hospitals. Again, it appeared that the proposals were driven by the need to make financial savings and members were particularly concerned about the absence of PPI in the development of the changes. The Trust’s view was that chaplaincy services were not legally a health service and therefore did not require PPI. However this view does not help to reassure us that there is a commitment to PPI running throughout the organisation.

16. A further area of concern that has arisen in Worcestershire is the issue of PPI by regional commissioning bodies, such as specialised services agencies and cancer networks. In the case of the latter, three cancer networks cover different parts of Worcestershire. The result of this is that in any PPI, Worcestershire’s voice risks being drowned out by the larger populations of the other areas within the network. For example, the three Counties Cancer Network covers both Gloucestershire and Herefordshire in totality, but only the southern part of Worcestershire.

17. Finally, we were very concerned that the recent consultations regarding the reconfiguration of strategic health authorities, ambulance services and primary care trusts, although legally not essential, offered no evidence that the proposed changes were strongly influenced by PPI. As we have said above, the credibility of PPI can only be ensured if commitment to PPI is embedded throughout the healthcare system, from the Department of Health down.

Conclusion

18. In our experience, although there is good PPI happening in some services, quite often proposed change within the NHS is put before the public at the stage where fundamental decisions on direction have already been taken and PPI is, in effect, only allowed to impact within pre-determined boundaries.

19. As we in Worcestershire are well aware, there may be political consequences of decisions taken by the NHS that are not in harmony with local feelings. On these occasions it should be possible to demonstrate PPI and offer an evidence-based case for the final outcome, which, although perhaps not welcomed, would offer justification of decisions taken. The alternative of simply bowing to public pressure for “political” reasons risks devaluing PPI.

20. Perhaps our key concern regarding patient and public involvement is whether there is genuine, ideological commitment to the strategy from the Department of Health through to primary care providers.

Recommendations for Action

21. In considering patient and public involvement in the NHS in Worcestershire over recent years, a number of areas for improvement/strengthening suggest themselves:

- Each NHS body should have a named officer responsible for co-ordinating PPI across the organisation. This post should be supported by representation at Board level to ensure PPI is taken into account at earliest possible stage of all work.

- Strategic Health Authorities could undertake a proactive role in ensuring robust PPI has been undertaken prior to formal consultation on service changes and reconfigurations.

- NHS bodies should promote specific, local examples where PPI has had a demonstrable impact upon the local NHS body’s initial approach.

Worcestershire County Council Health Overview and Scrutiny Committee

10 January 2007
Evidence submitted by Yorkshire and Humberside Specialist Forums (PPI 28)

THE CASE FOR THE “SPECIALIST” FORUMS

The situation of the “specialist” trusts merits particular consideration. While it is true that the 80% direct-funding for healthcare goes to the Primary Care Trusts, it should be understood that half of this is spent on commissioning hospital services.

Further, the “specialist” trusts (hospital trusts, ambulance trusts, mental health trusts and learning disabilities trusts) operate a highly disciplined scientific service that requires particular knowledge to assess. To subsume this activity within a social and community care setting is a distortion of the realities, and a dangerous one. It skews the emphasis far too strongly in favour of the commissioning PCTs and reduces scrutiny of the specialist sector to a sub-group status at best.

What is the purpose of patient and public involvement?

1. PPI Forums are not committees. True PPI connects the user with the service. It engages the skills and insights of the local users in a critical way to improve the services and build the confidence of the users. Most importantly, it must enshrine the independence to act and the power to make a difference.

2. This is a deep responsibility but an essential one. For a long time, there has been but a tacit deference to PPI within the healthcare system whose culture often finds it alien, and the increasing pressures imposed by the endless “reforms” from the centre have left PPI still far from the force for good it should be.

3. The public fund the health service and entrust themselves to it. They need to have active representation in the system.

What form of patient and public involvement is desirable, practical and good value for money?

4. PPI Forums have done a good job. Bearing in mind their short tenure, and the severe counter-influence of Commission for Patient and Public Involvement in Health, Forums have achieved an enormous amount and at very little cost. Forums should continue. They already have the outreach and interconnection that it is proposed will be brought through LINks, and they already have the cross-boundary working that enables oversight of seamless care.

5. PPI Forums mirror the actualities of the current configurations of the service. Every healthcare trust is a distinct institution, operates as a business in its own right, must achieve financial balance, has its own board etc. The present Forums’ model recognises this. The proposed LINks model would have most of the “specialist” trusts dealing with LINks from several local authority areas. Ambulance trusts operate across local authority boundaries and the hospital trusts’ services similarly are commissioned from a wide area.

Why are existing systems of patient and public involvement being reformed after only three years?

6. The official Department of Health line is two-fold. First, the Department says that “the nature of health and social care delivery is changing radically”. (Should this be so, it is solely attributable to the policies of the Department itself and more importantly, little of it will be apparent to the public at the interface. The Department constantly issues re-assurance that “it’s all the same, only better”) Second, the Department says that “more people want to become involved.” There is little evidence of this. If asked if they are interested in “being more involved”, most people will say they are, but few ever advance beyond this.

7. CPPIH has been from the start unsatisfactory and confused. The dissolution of arm’s length bodies spelled its death-knell and it leaves PPI Forums ostensibly parent-less.

8. Forums, despite the inadequacies of CPPIH, have been a constructive influence. They have confounded all expectations, triumphed over the shortcomings of the Commission, and become a force to be reckoned with. The Department of Health has shrunk from the reverberations of this powerful patient-voice.

9. Forums’ relationship of “critical friend” to their Trusts has refreshed the quality of the system and improved the services. The Department of Health, determined to market healthcare to the highest bidder and fragment it to the private sector, has a vested interest in being able to present trusts as “failing” in order to justify the sell-off. Forums have ably shown that most so-called “failings” are due to interference from the centre, interference often architected by the Minister.

10. The proposed LINks have been pushed on the basis that they will enable cross-boundary working and bring in user-groups, community groups and so forth. Such arguments stem from the ignorance in the Department of Health of the current system of Forums’ working, for in order to achieve this situation, no changes are necessary. Cross boundary working and involvement of other groups has always been part of the of the modus operandi of PPI Fs. “It ain’t broke so don’t fix it.”

11. The intention to site the host-organisation within the local authority is designed to enable the centre to abdicate responsibility for outcomes. (If PPI succeeds, the Department of Health can claim credit for the idea. If PPI fails, the Department will blame local mismanagement.) If the intention were truly to encourage
“localism”, there would not be the current interference from the Department, the insistence that PPI Fs must go and LINks must replace them. No evidence has ever been produced to suggest that this is what people want.

How should PPI be improved?

12. Outreach by PPI Forums to community and user groups and Forums’ interaction with others is a collaboration that already exists.

13. Forums should remain, at the centre of PPI. They form the natural and established hub for all those individuals and groups with concerns and interests in healthcare. Forums have a public profile, a distinct voice, and are a resource accessed by those with issues to be addressed, by opinion makers, media, etc. Forums have the respect of their Trusts, a developed knowledge of their services and systems, and a statutory mechanism for co-working with a remit of safeguarding standards.

14. Forums provide a necessary resource for their Trusts who use them to accredit their services. The independent and informed assessment by Forum-members, whose relationship with the Trust is embedded and on-going, is vastly more meaningful than the isolated snap-shot in time of a rare Healthcare Commission inspection.

15. It has been said that “PPI is always the same people” but this is no criticism, rather a recognition of the realities. It is simply not true that there are thousands of people out there panting to be involved in PPI. Only 2% of respondents to “A Stronger Local Voice” were members of the public and the Department of Health, with all its resources, could elicit from the whole of the country only 500 responses to its document “A Stronger Local Voice” (see “Government Response to “A Stronger Local Voice””) yet last year, nearly 20 million people used A and E services alone: the interactions between the public and healthcare run into countless millions. Against this, the 500 responses to “A stronger Local Voice” are statistically insignificant. However, it should be noted that the majority of the responses came from those actually involved, PPI Forum-members.

16. It has also been said that PPI Forum members are predominantly “white, middle-aged and middle-class”. So are members of Parliament. Putting up for Parliament, like putting up for PPI, is optional and dependent on the motivation of the individual. Some are minded to serve. Many are not. This is no grounds to criticise and abuse those who do. Rather, they should be applauded. Ppi is never going enlist “everyone”, nor would it be workable if it did: it operates by eclectic representation. It is a means for voices to be audible and influential, not a Noah’s ark to house every specimen of humanity.

17. Funding must be ring-fenced and devolved to the local level. The CPPIH has used up the lion’s share of the PPI budget under the current system. The 134 members of CPPIH staff have taken more in expenses in the last year than all the 4,000 plus Forum-members put together. The money has been used to poor effect by the Commission. Had the money been available locally to scope the work of Forum-members, managed locally as required by the Act, the achievements of the Forums would have been even more remarkable.

18. The independence of PPI is of paramount importance. Forums currently have that independence but the new proposals, advocating that host-organisations should be selected and contracted with by local authorities, and that the new membership be appointed by this host-organisation, risk jeopardising PPI with the taint of politicisation. Further, many local authorities have little interest in devoting time and energy to setting up these “hosts”.

19. Many of the Forum Support Organisations currently supporting PPI Fs are excellent. Forums know which these are. It makes sense to retain these as they have proved their worth. Support must be local. The CPPIH practice of dispensing with those FSOs which could not or would not support large clusters of Forums is a mistake. CPPIH defended this on the grounds of rationalising to economise, an irony not lost on Forums.

20. The funding should be used on the front line. Pro-active PPI uses money which historically has been reimbursed retrospectively. This has mitigated against those Forum-members with little or no disposable income and has hampered, even stalled their work. There needs to be a support system to accommodate ready access to funds.

21. The CPPIH has proved very poor value for money. Communication and support from the Commission has been lamentable and the so-called training-provision derisory. The benefit from the Commission to Forums and their work has been nil. The Commission has misrepresented Forums’ views and wishes and has often actively abetted initiatives to restrict and hamper them. Ultimately, CPPIH has been the prime architect of the current proposals to dismantle PPI Forums. This is a disgrace.

22. The current powers of PPI Forums must be retained and it must be made clear that the right to enter, inspect and report (“visits”) applies to the independent-sector where NHS activity is undertaken, as well as to NHS premises.
23. The relationship of PPI Forums with local health trusts is well established as “critical friend”. It would be both stupid and dangerous to destabilise or dismantle this. These dedicated relationships have taken time to build up and are bearing real fruit. Both parties wish the status quo to remain. (For example, Bradford District Care Trust freely chose to involve and use the PPI F as its only vehicle for PPI and exchanges with patients and public. This choice by BDCT represents an important change and improvement in an evidence-and choice-based NHS.) Trusts are already under too much and too relentless pressure to contemplate change here. To meet the Core and Developmental Domains of the HCC’s assessments, Trusts are reliant upon their Forums.

24. National co-ordination for PPI is in hand through the pending elections for the long overdue National Association of Forums. This will at last circumvent the quasi-professional “talking heads”, from CPPIH and elsewhere, who with no justification have claimed to speak for Forums. The National Association should also obviate the soaking-up-of-funds at the centre.

How should PPI relate to and avoid overlap with OSCs?

25. OSCs are first and foremost political, elected representatives. They have no claim to be knowledgeable on health matters. They meet according to a local government timetable, and receive presentations from health-professionals. Many OSCs have allocated places to PPI F members and thus enriched their understanding. It is recommended that this become the norm. Forums can be called upon by the OSC, at short notice, to follow up concerns, enter and inspect. The relationship should be symbiotic: Forums can refer matters of concern to the OSCs, the OSCs should elicit the help of the Forums to scrutinise and report.

26. Foundation Trust status alters the governance and financial remit of a trust. It does not confer infallibility in clinical care. The Trust still provides services to the people of the patch and there remains the need for totally independent PPI.

Why should the “specialist” trusts be an extra ordinary case?

27. The Department of Health is fixated on community, health-outside-hospitals. The PCTs, now aligned with the local authorities, hold the purse-strings. The enormous, far-reaching and rapid changes unleashed upon the healthcare scene from Whitehall continue remorselessly and Trusts are already reeling.

28. The “specialist” trusts’ situation is different from that of the PCTs. The “specialist” trusts have very large fixed costs, high overheads, and carry responsibility for unplanned and emergency care 24/7. They are reliant on high-tech and expensive hardware, equipment and communications systems. They are a vital part of civil contingency response to threats ranging from terrorist attack to avian influenza. They play the key role in training and research and clinical innovation. Their planning has very long lead times, involving immense investment before any income from activity. The D of H’s current insistence on in-year financial balance is wholly unforgiving of all this. Its constant shifting of goal posts is irresponsible, unnecessary and particularly punishing to the “specialist” trusts. The “specialist” trusts’ abilities to accommodate to all this, even if it were clinically desirable that they should, is very limited. Much of this is ill understood in PCT-land, even amongst the commissioners themselves. The “specialist” trusts need their dedicated PPI Fs as their advocate, champion and ambassador as much as they need them as their critic, scrutineer and clinical-conscience. The Department of Health and the government will also obviously benefit from the continued expert input of PPI Forums.

Ruth Marsden
on behalf of the “Specialist” Forums of Yorkshire and Humberside
6 January 2007

Evidence submitted by Louise Bate (PPI 95)

1. The purpose of patient and public involvement is to improve the delivery of healthcare. To develop a patient-led NHS, patients and the public need to be actively involved in the planning, design and delivery of healthcare services.

2. PPI Forums have had limited success because the membership process and committee model isn’t flexible enough to actively encourage public participation. Currently a PPI Forums success is dependent on a good Chairperson and a committed membership, but this is not often the case. Volunteers without experience of committees are discouraged from participating by the lengthy application process, mountains of paperwork and the structured approach.
3. LINK’s should therefore be designed to be more flexible, allowing people to participate on different levels. LINK’s must be independent of the NHS, in order to avoid conflicts of interest. They also need to be supported independently of the Local Authority, in order to avoid political pressure. There needs to be some form of national co-ordination, to gather trends and issues. The DOH should take responsibility for nationally advertising LINKS in a similar way to the current information about ICAS and PALS.

4. LINK’s should be designed to work closely with OSC’s, the Healthcare Commission, ICAS and Foundation Trust Member Councils. Their purpose should be to actively encourage patient & public participation and to share information with all relevant stakeholders.

5. Section 11 of the Health and Social Care Act 2001 needs to be made clearer. Currently Health Trusts and OSC’s are left to guess at whether a situation will be considered a “substantial variation”. Public consultation by Health Trusts is often an afterthought, more about ticking boxes than actively encouraging public participation and comment.

Louise Bate  
PPI Forum Development Officer  
10 January 2007

Evidence submitted by Jennifer Beesley (PPI 41)

I joined the local PPIF be able to use my many years of knowledge in health for the benefit of ALL. This summary is of my experience of the PPIF and why I believe is not fit for purpose and most certainly does not give best value. The most important role of the PPIF is to represent the views of the local population, but do they do this?

The annual budget of £38 million for PPIF is a huge amount of money and there must be a question on its effectiveness to give the public a voice when FSOs run the organisation with their own agendas.

CHCs were generally known to the public, but after three years still there is a vast majority of the public who still have never heard of PPIF—WHY!

PPIF meetings should all be held in public, and encourage public participation; not closed meetings and refusing public questions. It is important to listen to the public in different arenas to establish and identify their concerns enabling the forum to carry out surveys/work etc.

The PPIF membership must be from all walks of life, many may not want to fully participate but they should not be made to feel second best. Disabled people need a great deal of support to enable them to participate and that should be forthcoming, not only by other members but the FSO as well.

The time delay to process new members is unacceptable. The CPPIH seem to drag their feet, and therefore people then lose interest.

CPPIH need to be abolished now. I have experienced nothing but complacency. The CPPIH surveys requesting comments on FSOs from your forum are ignored, and complaint are never satisfactorily responded too. The CPPIH has the powers to enable them to run a superb organisation, but no one seems to have the ability to ACT. What has gone wrong! This organisation could have been a very great asset in training, support etc, but always seems top heavy with management.

Section 11 is a very great asset for forums to carry out surveys and speak to the public about issues, while visiting NHS establishments, which are important to them. The independence of forums and their members have enabled them to work as “critical friends” with PCTs.

On many occasions PPIF's have spoken to PCT Chief Executive and drawn their attention to public concerns, which they have then been addressed for the benefit of many. (eg: GUM Clinic)

Great Yarmouth PPIF forum embarked on a GP survey to establish how well the public could access appointments. With NO help from our support organization we analysed 687 questionnaires and received 1,477 volunteered specific comments. Published April 2006.

Each PPIF Annual Report is something which should show the public what has been achieved during the year on their behalf, but do they?

Our members have been refused access to examine their forum yearly expenditure relating to the support agency (to ensure best value) due to contractual confidentiality.

The Annual report template is something worth looking at. Copies of all annual reports are sent to the local SHA. Perhaps comments from them on the composition and contents would give the committee some ideas of forums work and best value.
East of England SHA comprises of 69 PPI forums—why so many?

The new reconfiguration of PCTs has brought a greater role on PPIFs. The smaller and some times more active PPIFs have been swallowed up, and in some cases members have left. Leaving some areas only represented by one PPIF member. Was this destruction of smaller PPIF really necessary?

Up until Links, the CPPIH and PPIF will have been independent organisations. There can be question of conflict of interest with members dual NHS roles which the act is very specific on, but the CPPIH lacks the ability to carry out their statutory duty is to ensure members are as independent as their organisations. Members of any public body must remember The Nolan Report on conflict of interest and the public perception, and in turn the CPPIH should also fulfill its statutory duty.

LINKS can be a wonderful way of involving the public but allowing CC to control the budget without ring fencing is ludicrous. They will, as always, top slice the budget—and further more, how can they scrutinise some thing they are controlling?

The County Council OVS committee locally has a tendency to have working parties but they never seem to finish their work! When PPIF take serious concerns on bed closures to them, yet another working party is set up and the finding never come back to the OVS committee. Then its all to late, a year on.

Conclusion

During the time I was a member and a Chairman of a PPIF, I found the biggest battle was dealing with the FSO who never wanted anything to be open & transparent. The CPPIH were supportive on many occasions but were often inconsistent with advice. Perhaps with LINKS it may be better overall, but so far I am not convinced that the public want to get sufficiently involved in the work that is required.

The lack of Audit of such a large quango is concerning and to restructure it within three years is, at first impressions, irresponsible But is it?

After being part of this organisation and seeing its ways of operation and organisation I would say: no there is a better way, but perhaps not quite so drastic.

The future of PPIF or Links should be far more public friendly. Meetings should not be at 9 am in a morning to suit the Chairman but at different times enabling people who work to attend.

Will Links make the change that the government wants, and will there be sufficient new members? I very much doubt this, as apathy brings health to its lowest ebb.

The PPIF/Links, or what ever it may be, must look to the future with openness and optimism for successful working with the public, and not allow weak support organisations to destroy them.

Jennifer Beesley
6 January 2007

Evidence submitted by Judy Birch (PPI 101)

I am submitting the following comments in my role as a patient and patient representative who has been involved in working in an independent, voluntary capacity for several years at local, national and international levels. I have attended and spoken at many medical conferences both in the UK and abroad and also in the UK and European Parliament. I have been a member of the local PCT PPI forum since forums were established in 2003 and have recently established a charity for an area of medicine where there has been little patient representation.

1. Remit and Level of Independence

It is essential that patient involvement is independent of the NHS and that the power of entry to inspect NHS premises is retained by a number of forum/Links members who have undergone CRB checks.

Health Scrutiny Committees comprised of councillors are not independent. Representation on OSC’s of one forum/Links member will have no effect/benefit.

If there is to be closer working between forums/LINKs and OSC’s, there needs to be a greater balance in the number of lay/independent representatives from Links.
2. Membership and Appointments

It would be beneficial for the forum support organization to explain the role and functions of the forum/Links to prospective members. This should then be followed by an opportunity to meet and discuss how they would best fit into the forum with the existing members.

Currently FSO’s are meeting with NHS staff and discussing forum business without the knowledge or input of the forum. This is not the purpose or the idea of patient involvement. Again it is others taking over and acting on behalf of patients and the public which is not true representation.

3. Funding and Support

Funding needs to be sufficient to support the activities of the forum. The support should be independent (not sure that this is the case at present) Links should have the funding and resources to carry out wider consultation/research.

4. Areas of Focus

Less common conditions need greater attention with a focus on quality of life issues rather than disease specific. There is a great deal of inequality in this respect with some diseases gaining unprecedented attention at the expense of other equally deserving but less glamourous conditions.

5. Statutory Powers

It is important that forums/Links have the powers to obtain information in the public domain. There have been cases where this information is public but PCT/Trusts have not wanted to disclose it. It is also important that they can monitor and inspect premises. See paragraph 1.

6. Relations with Local Health Trusts

There have been many instances of good relations developed with local trusts and much greater communication than prior to the existence of forums. This should be encouraged and maintained.

7. National Coordination

This has currently been coordinated by the CPPIH. There have been examples where forums were not aware of CPPIH involvement such as the latter's support for the APPG on Patient and Public Involvement. Any system must be transparent and welcome PPI input and involvement in a meaningful way.

8. How Should Links Relate To and Avoid Overlap With:

OSC’s—please see paragraph 1

Foundation trust boards—these are also not independent, there should however be communication between them and Links.

Healthcare Commission—Links should have input into the work of the HIC commission

Formal and informal complaints procedures. Links do not deal with individual complaints but PALS is not independent and patients frequently report difficulties with the non-independent nature of the latter.

General matters relating to PPI

Currently patient representation at national medical conferences organized by the Royal Colleges, hospitals and organizations such as NICE, the NHS Alliance is severely restricted either by the non-existence of a category of attendance for patient representatives or by prohibitively expensive rates amounting to several hundred pounds for one or two days attendance. This is hardly encouraging participation and involvement from those who have an interest and a duty to represent patients on a voluntary basis. There should be a requirement to provide a concessionary category of attendance for relevant patient representatives at such events that is affordable and substantially lower than the attendance fees for PCT Chief execs and others who have their costs covered by their employers. In many European countries the latter is the norm and such events are open to patients as well as patient representatives at a very nominal, affordable fee. Such involvement would generate a greater interest in independent health research and involvement by patients and the public.

Judy Birch
January 2007
Evidence submitted by Susan Booth (PPI 94)

Local Involvement Networks

1. The name means nothing. For the past ten years I have received two newsletters from local organisations called LINK. Away for Christmas I found a weekly one.

2. The Community Health Councils and the PPI Forums both drew people from local organisations. The North Staffs PPI Forum now includes two previous forums each with different branches of the “local” organisations. Are all branches to be included/recognised?

3. How is this unwieldy body of people to be organised to work? Some of the PPI Forums now are too big to organise their work properly. Talking to members of other PPIFs it would appear their ability to work often depends on the quality of the Administrative Support they are (or are not) given by the FSOs. Can Local Authorities give this support? Para 1.27 of “Government Response to “A Stronger Local Voice” (Gateway Reference 7283) hardly seems workable when there is more than one local authority involved. And a county authority may have to work with more than one LINk.

4. Since I understand there are some Councillors who have no idea what they should be doing at the moment, it is going to take some really good communication to explain LINk to everyone who is going to be involved, much less to the general public.

5. As they stand the PPI Forums could work (should be working) with other organisations—the simple way to involve them would be to co-opt one representative to the PPIF. They need not be CRB passed. They would bring their situation and requirements to the Forum and help on working groups (as I understand some Fora do already).

I am 75 years old and I have lost count of the times where Senior “Management” have brought in changes which look good from the top but as they haven’t looked thoroughly at what happens at the bottom before bringing in the changes, work has stalled while people learn how to work in the new (and often not better, easier or more effective) way.

Susan N Booth
North Staffordshire PPI Forum (comments are made as an Individual)
10 January 2007

Evidence submitted by Malcolm Budd (PPI 84)

As a civil engineer and cave explorer of 65 years, the contribution I offer comes out of an especial interest in mental health from 30 years of manic depression and over a decade of recovery since being “sectioned” and staying in hospital for some three months in 1993. I am now fully recovered including no longer in need of medication and enabled to regain my professional work albeit in a different field.

This includes teaching in mental health at the University of York, assisting in the development of a new £10m mental health facility in Airedale in West Yorkshire. I am a Director and Trustee of the Cellar Project, a mental health charity providing workshops’ experience to aid regaining personal and social confidence and skills for dealing dealing with serious mental ill health problems. I have been a member of the Bradford and Airedale Primary and Bradford District Care Trusts Patient and Public Involvement in Health Forums since their inception. I offer as a freelance my “Independence of Mind” Workshop for which I attach the guidelines.

My experiences in mental health, heavy civil engineering and cave exploration and rescues all lead to the conclusion that the future of the National Health Service, its patient and patients has been, and will be well served by the PPI Forums as presently constituted. In an era when regretably too much power and attention is given to management and its structures, the original intention and decision of Parliament to pass the 2001 Act which instigated the PPI Forums has proved sound, with the possible exception, now the Forums are established, of now reducing the size and budget of the Commission and its offices, as its main original task has been achieved. With the latter I feel the evidence shows the Forums operate and act most in the interest of the whole and the local health care needs if they retain their existing structure of unpaid and unelected volunteers, low costs and freer association between members. The Forums, without the constraints of a committee structure, act together to look at the evidence and agree a course of action. Thus retaining intact the beneficial effects of the experiences and knowledge of the individual members, especially in mental health where the varying detail and nuances of the individual are critical to the individual’s improvement. And the Forums and their activities fit well into the framework of the professional Healthcare Commission and the democratically elected Overseer and Scrutiny Committees within Local Authorities.

My experiences and personal “success” at recovery have lead me to the view that mental ill health and its nature is much misunderstood partly out of the legacy of it the practices and terminology of physical medicine and the approach of the “pseudo-science” of psychiatry. The serious doubts about much present
practice is reflected in my Forum work and view that the Forums' essentially democratic, “bottom up” is an important feature and has critical effects in dealing with “top down” management methods and structures of the Trusts when representing patients and public in our local communities.

I feel it is particularly important that the Forums are not committees and are not dependent on and limited by, Trust structures or geography. They are thereby enabled to take a broader and more community view rather than be constrained within the Government and Trust policies’ envelopes. The powers parliament gave the Forums are an important element in our democracy both national and local. Whereas the present Government’s new proposals, not yet discussed or approved by Parliament, are much narrower and closer to the existing public bodies and the effects of their management inclined structures. It seems to me the trust Parliament placed in the volunteer Forum members has been well rewarded. So it is especially perverse after only three years, when they have just become established and effective, to abandon them and their structures and methods. To bring about the faulted changes proposed before the Forums have completed the job they were asked to do will only further disconcert and dismay Forum members, patients and public alike.

I acknowledge there is need for change but it seems to me change has become a mere fashion at a time when the NHS and our society has a need for continuity and greater recognition of the need for the experienced, knowledgeable and skilled rather than the near obsession with management and monetary views and methods.

It has been my experience by choosing appropriate staff and supporting them with trust and fitting resources and minimal management interference the best outcomes can be obtained. I do wonder what was the point, post War, in ensuring a well educated, informed and healthy population if we then do not offer them the cooperation and trust they have earned and deserve. This approach is especially fitting and beneficial when applied to the PPI Forums and their members.

I earnestly ask the this Select Committee to reject the Government’s proposals and support the continuing practical and valuable work the PPI Forums are doing to improve the NHS and offer the wider public direct and unbiased ways of making its views and needs known.

Malcolm Budd
9 January 2007

Evidence submitted by Judie Collins (PPI 10)

I have been a PPI Forum member for the last two years and would like to make the following comments relevant to your inquiry.

I am a member of a PCT Forum which obviously as the PCT is a commissioner and provider links to other local NHS institutions. We have two organisations looking after us, our Forum Support organisation and CPPIH. I have experience of meeting other forum members from across the country. They suggest to me that the experience of Forum members varies according to how efficient and helpful their FSOs are. We are on our second FSO and when we are surveyed about their support for us we have always been highly critical. We have also made extensive efforts to go to CPPIH with our concerns without success.

Some PPI Forums are happy to concentrate on individual health issues particularly in hospitals like MRSA, Paytalk etc. CPPIH’s publicity seems to reflect this. However we have spent the last two years fighting what we consider to be major injustices and failures to provide a good health service for the residents of our area.

Three Examples

Two years ago shortly before Christmas one of our local hospitals was closed over night citing safety grounds. It was proposed to move elderly dementia patients to a remote part of our mental health care trusts’s territory. We fought with the relatives and despite initial denials a facility was eventually found close at hand where they are now close to home.

18 months ago our breast cancer service was closed again over night. Since then an inquiry has been continuously delayed without proper explanations. The interim service is proving inconvenient and has been plagued with administrative problems. Our provider, commissioner and the SHA have run rings both round us and our OSC and continue to do so.

Two rehab wards were closed without consultation and as our patience had by then run out we backed the community in going to a successful judicial review. We are at the start of a public consultation which is proving problematical and despite seeking advice from all the above organisations plus the Health Commission plus the Independent Reconfiguration Panel no one at any time has been able to explain to us where we can turn for help. Even the advice from the Secretary of State has conflicted with what we have been told locally.
We have had no problems in getting access to the most senior officers at our Health Trusts and are on most committees and project boards which we understand is quite uncommon. We do however face a constant changing of senior officers so the ones who left can be blamed for whatever has gone wrong. Also our PCT and Health Trust don’t get on. Neither get on with our Mental Health Care Trust. Our council don’t get on with our health trusts and social services never turn up to health committees or boards they are on so joined up working proves impossible. We have found our OSC which has been reconstituted several times refuses to face up to its challenges and our mentoring of disadvantaged groups elsewhere leads us to believe that OSCs just don’t have the grasp of legislation to do their job properly. The thought that councils might have some power over us in LINKS fills every forum member I have spoken to with horror.

In the Greater Manchester area we have been deluged with public consultations and again we are frustrated because they don’t reach the public, the cabinet code of practice is not adhered to and the public who we represent is left with the distinct impression that the results are fixed.

Will the situation be improved by dismembering PPI Forums. Given how long it has taken our forum to get to a stage where we feel we have earned the respect of NHS management I don’t think so. The Forums work well, it is the support for them which is inefficient and costly. Firm up the Forums powers and give them adequate support.

Judie Collins
January 2007

Evidence submitted by Mike Cox (PPI 21)

Introduction

I am a National Health Service user with a long standing (30 years) involvement in service user and carer involvement. Since 1999 that has taken an increased focus on the development patient and public involvement in health and since December 2003, specifically on Patient and Public Involvement Forums, the statutory replacement for Community Health Councils.

Since resigning my PPI forum membership in February 2004, disability discrimination being the last CPPIH straw for me, I have done my best to function as an independent watchdog for the constructive development of PPI. In 2005, I set up my own website to further this function (PPEyes) but this was closed down in the Autumn of 2005 by the intervention of CPPIH appointed lawyers who alleged defamation (there is legal precedent that a public body cannot do this). The details of this and the evidence of CPPIH incompetence and equivocality is in the accompanying html dossier.

I have in the past, also, via my constituency MP, Richard Bacon, and direct reference, been in touch with the Health Committee about these issues and I did submit a paper Recommendations on PPI reorganisation to Meredith Vivian in August 2004, some of which remains relevant to you and which I have also included.

There seems to have been a surprising absence of organised service user led research in this sphere, particularly since service users and carers have battled to get their voices heard as credible, legitimate and truly independent—free from attempts at interference and influence by professionals and free from attempts to manage, control and direct by corporate interests. That movement should be synonymous with Patient and Public Involvement in the NHS.

The term ‘service user’ is preferred to ‘patient’ because the term ‘patient’ has, over the years, gathered role expectations which include subservience, passiveness, helplessness and ignorant—someone who has things done to and for them with no involvement of their own. ‘Service user’ is one who uses services with a right to choose and provide their own input, in an equal partnership with the professional/clinician as an expert on themselves and their own circumstances.

PPI Forums with their statutory identity and powers established by the National Health Service Reform and Health Care Professions Act 2002 along with section 11 of the Health and Social Care Act 2001 should then offer huge benefits for the development of real service user and carer independence of thought, voice and action.

What is the purpose of patient and public involvement?

1. “... in recent years, the needs, views and rights of NHS patients have rapidly ascended the political agenda, with the Government announcing in 2000 their ‘vision’ of “a health service designed around the patient”. While measures to improve access, convenience and quality of care for NHS patients form the mainstay of government policy, there have also been significant developments in terms of securing direct patient input into NHS services, and providing enhanced support to patients negotiating the NHS system.

70 Not printed here.
71 Not printed here.
The role of PPIFs is to influence the day to day management of health services by the Trust, and to monitor the effectiveness of the PALS and ICAS in their area—be the main vehicle for the public to influence strategic priorities and day-to-day management of health services in their local area; be an independent critical friend on wider health matters in their community such as environmental health; review services from the patient perspective and monitor responses from local health services to complaints from patients.” (Patient and Public Involvement in Health, Health Committee, 7th report, Session 2002–03).

2. “It is important to recognise that, for too long, decision making in the national health service has been behind closed doors and that all too often it has resembled a secret society rather than a public service. We have to open it up to all sections of society because the national health service does not serve just one part of the community; it serves the whole community and we must have a means of decision making that properly reflects all interest groups . . . The Bill strengthens the patients’ voice inside the NHS. The CHCs had no role in primary care; patients forums will have that role. The CHCs were refused the right to inspect GPs’ premises; patients forums will have that right. The CHCs were partly appointed by the Secretary of State for Health; patients forums will all be appointed independently of both the Secretary of State and indeed the NHS. The CHCs had no formal rights of representation within NHS organisations; patients forums will elect, as of right, one of their members to sit on every trust board. This is about not diminishing patients’ rights in the health service, but increasing patients’ rights in the health service” (Alan Milburn, Commons Hansard 2001).

3. In my opinion, the concept of PPI as outlined above is positive. It has been the execution of the purpose which has been dysfunctional.

What form of patient and public involvement is desirable, practical and offers good value or money?

4. It is clear that the structure of PPI should be democratic, service user led and run and “bottom-up”. It is a fundamental and very expensive mistake to try to impose top-down governance via corporate management structures.

5. True independence is a basic requirement. For example, many PALS bodies only function partially because they are part of the trust organisation itself and are subject to both formal and insidious pressures to conform to the needs of the organisation.

6. It is obvious that the use of volunteers offers good value for money. However, it is essential that volunteers are afforded full respect and full rights. I would say the resignation of 2,248 volunteers from PPIFs by October 2005 was a reflection of the CPPIH’s regular mistreatment of its volunteers.

7. Finance should be arranged through a separate independent financial trust. Funding through local authorities means PPI having to conform to requirements written into contracts which could conflict with the objects of PPI—subtle “gagging” clauses for example. Funding provided to local authorities by central government for PPI will, unless ring-fenced, proportionately disappear into other budgets. The same applies to NHS bodies.

8. Standards in Public Life should apply throughout PPI.

9. Public accountability must have clear, known channels and solid remedies. For example, it has been impossible to hold CPPIH to account for maladministration: (a) referring unresolved complaints to the “parent body” (DH and Rosie Winterton) as advised by both the Office of the Parliamentary and Health Service Ombudsman and the Office of Standards in Public Life has just resulted in the complaint being passed back to CPPIH to deal with; (b) referral to the Parliamentary Ombudsman has just brought a response that complaints cannot be dealt with because matters to do with CPPIH volunteers are judged to be “personnel matters” which, by law, cannot be dealt with by the Ombudsman.

10. There is nothing wrong with the existing PPI Forums if they are organised in these ways, indeed, the stronger examples have set some standards which could be built on despite CPPIH maladministration. Why waste money and throw away this hard earned fundamental learning?

Recommendations

11. The body or partnership responsible for the governance of PPIFs should employ, or engage volunteer service users and carers as experts in their own right to oversee PPI, at every level, on an equal footing with all employed staff.

12. The body responsible for the oversight of PPI should be accountable to a Parliamentary Select Committee with a facility for direct referrals to that Committee by service users, carers and other members of the public.

13. There should be a change in the law to enable complaints by volunteers about PPI to be accepted by the Parliamentary and Health Service Ombudsman and not thrown out because they are “personnel matters” as is currently the case.

14. All personnel responsible for the governance of PPI should be brought under the remit of the Standards Board.
15. Any PPI organisation should have a clear and accessible whistleblowing policy with readily available links to whistleblowing bodies such as Public Concern at Work and Freedom to Care (Freedom to Care’s code on accountability should also be considered).

16. Volunteers should be brought under the ambit of the Public Interest Disclosure Act 1998.

17. Any internal complaints procedure should be carefully revised to simplify it and obviate possible misuses of power. An independent agency (eg the Healthcare Commission) should monitor second stage complaints.

18. Volunteers should be afforded the same protections as those in employment law and have the same rights as employees to have matters heard by an Employment Tribunal.

Why are existing systems for patient and public involvement being reformed after three years?

19. The concept of PPI as outlined above and as in “Strengthening Accountability” is good. The installation and implementation by a top-down civil service management bureaucracy which ignored the 30 years’ plus expertise of service user organisations and individuals has been disastrous. We must learn our lessons from this.

Recommendation

20. CPPIH should be immediately removed from the re-organisation process and this should be conducted by a federation of service users and carers.

How should LINks be designed, including remit and level of independence

21. PPI Forums should remain, with their current remit, at the core with three completely independent clusters: local voluntary organisations; PALS; and ICAS. LINks should be flexibly organised and responsible for their own local bottom-up planning, development and operational functions. Flexibility is essential to take account of the huge differences between metropolitan, urban and rural conditions. Rural policies must be “Rural Proofed”.

22. PALS has to be fully independent as the first line casework body—employment by NHS trusts inevitably potentially creates divided loyalties with most being resolved on the side of the body which pays the wages. There must be tight communication and operational LINks between PALS and Forums.

23. See also 5.

Recommendations

24. Process and meetings should ensure at least equal access to those living in rural areas. Positive discrimination in favour of those living in rural areas may be appropriate and required in some instances. All policies and procedures should be “Rural Proofed” as a matter of urgency.

25. Where trusts cover large geographical areas a core and cluster approach should be adopted. There should be full local exploration of alternative means of attachment, ie “patient journeys”.

26. There should be avoidance of a position in which one person can dominate the team to pursue their own agenda.

27. See also 30.

Membership and appointments

Recommendations

28. Recruitment should be managed by a partnership between a National Federation of Service Users and the PPI Centre for Excellence.


30. In the interests of real PPIF independence and a minimisation of vested interests and conflicts of interests, the regulations should be revised to exclude any person with a continuing NHS or Social Services or other corporate commitment whether employed or not. There should also be a requirement for members to be publicly open and transparent.

31. The regulations should link to a freely and publicly available PPIF Code of Practice. There should be a review of the current membership with these changes in mind. that review should include and examination if paragraph (3) (a) of the Membership and Procedure Regulations 2003 is being observed.
32. The parameters and regulations related to welfare benefits should be reviewed to minimise deterrents for service users' and carers' full involvement in PPI.

33. Recruitment and appointment procedures should record an assessment of prior experience and an assessment of prior learning for each member.

34. Recruitment and appointment processes should involve service users and carers.

35. The new governing body should, from the earliest date, individually engage existing forum members in an appraisal of present skills, knowledge, abilities and experience towards an assessment of immediate training needs.

36. The above appraisal process should be part of the recruitment and appointment of new members and should be conducted by the PPI Centre for Excellence.

37. Essential training needs should be met at the point of the appointment of forum members and there should be a secondary rolling programme of training which is regularly reviewed in partnership with the above organisations.

38. Education and training should be competent and rigorous continuous processes and not something tacked on as internal amateur activities by management and administrative staff.

39. All training and education processes should involve service users and carers.

**Funding and support**

Recommendations

40. In their 2001 document “Making it Work Together”; the Scottish Executive in the Section headed “Ideas on how to ensure independence”; said: “Keep funding at arms length by considering setting up an advocacy trust for your area—by pooling funding from different sources so no one agency holds the significant funding responsibility. . .” That concept should be adapted to LINks.

41. Support should be provided by the Centre for PPI Excellence (knowledge, guidance, advice) and an integral part of LINks providing administrative facilitation on the lines of the proven FSOs. Those FSOs which have proved to be dysfunctional (eg those who have imposed management decisions on Forums) should be excluded.

42. New organisations or groups used for PPI facilitation should, wherever possible, be service user and carer run. They should take account of the special needs of rural areas.

43. See also 7.

**Areas of focus**

44. Foci and priorities will differ according to the local needs, circumstances and social structures. They should be determined bottom-up by the LINks themselves.

45. A special concern is that recent NHS re-organisation has created vast PCTs covering thousands of square miles (ie Norfolk PCT). Particular attention should be paid to the problems of how the “local” element in LINks can relate to these new leviathan like bodies, especially the planning and delivery of mental health and learning difficulties provision in primary care.

Recommendations

46. The building of LINks should start from local community/neighbourhood level, and the term “local” should be defined as such.

47. Consideration should be given to developing small “portfolio” groups (eg mental health, HIV/aids, learning difficulties, drugs and alcohol) as PPI clusters in areas where one PCT covers a large geographical area.

**Statutory powers**

48. No change.
Relations with local health trusts

Recommendation

There should be two PPIF service user places on each NHS trust board.

National coordination

Recommendation

50. A National Federation of Service Users should be established to oversee PPI and advocate for volunteer rights. This should include existing Service user run organisations such as Shaping Our Lives, Together and MIND.

How should LINks relate to and avoid overlap with:

Local Authority structures including Overview and Scrutiny Committees

51. PPIF relations with OSCs are already good in some places. That should be enhanced by measures to ensure closer working between LAs and NHS being introduced elsewhere. The formation of LINks should further strengthen relations.

52. The questions being asked are around how effective examination by OSCs is proving—where does it go from there in terms of addressing serious issues. As shown in the Health Committee interview with Rosie Winterton last year, referrals to her department appear to get lost in the in-tray.

Recommendation

53. The legal powers of OSCs should be strengthened and shortened.

Foundation Trusts boards and Members Councils

54. As in 49.

Inspectorates including the Healthcare Commission

55. See 17.

Formal and informal complaints procedures

6. In what circumstances should wider public consultation (including under section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

Recommendations

56. One model for consideration should be local high street shop front premises for each PPIF with administrative and secretarial support on hand. This will maximise truly local involvement.

57. Activities should focus on processes rather than events. Reaching out to consult service users, carers and members of the public, especially those who are disaffected and those who have communication difficulties, should be a priority. Making decisions and taking actions based on forum members' opinions, however well informed, should be discouraged. There should be a focus on “evidence based” processes.

58. There should be a positive “reach-out” policy as the primary activity of PPIFs and some elements of LINks. Other agencies (ie drugs and alcohol services, Learning and Skills Department projects) have developed good practices here and PPI can learn from these. For example, small two person “surgeries” in libraries, gp premises, hospitals, village halls, local pubs etc.

59. PPIFs should be encouraged NOT to organise themselves as formal business committees. A “team” approach operating on more “organic” lines would seem more appropriate with team members taking on overlapping roles: ie liaison, local contact, advocacy, public speaker, etc.

60. Norfolk County Council has published excellent disability guidelines for making public consultation possible “Accessibility Matters”: PPI should use these.

Mike Cox
PPEyes

2 January 2007
Evidence submitted by Seton During (PPI 24)

What is the purpose of patient and public involvement?

1. To praise where due and notify about strengths, weaknesses, errors of omission and commission about any and all aspects of health services provisions and deliveries, and, if capable, recommend optimisations.

What form of patient and public involvement is desirable, practical and offers good value for money?

2. Good starts are existing variegated forms of PPI Forums as credible workable imperfect foundations.

Why are existing systems for patient and public involvement being reformed after only three years?

3. Because Central Government and Parliament are congenitally wasteful, and in these respects have nebulous senses of purpose and direction, poor value judgements, and lack the moral courage to publicly confess what they really want.

How should LINks be designed, including:

4. For optimum economic management of changes, start with all existing PPI Forums; optimise from a central generic “guide” to sustain continuities and accommodate changing local desired objectives variegatedly with a sharper lookout for fraudsters.

Remit and level of independence

5. As currently applicable to/for existing PPI Forums.

Membership and appointments

6. As currently applicable to/for existing PPI Forums with better diversities, a sharper lookout for commercial lobbyists; and, enhanced criminal records bureau checks certification.

Funding and support

7. As currently exist—with less expensive top-heavinesses and no more.

Areas of focus

8. As currently exist as foundations for enhancements/innovations, eg hygiene; better education; diseases of the young (STDs); mycoplasmas/man-made diseases—AIDS/HIV; medical errors; educated utilisations of feedback from pathologies; adverse(-side) effects approved drugs; non-NHS/private practices; excessive unethical monopolist influences of pharmaceutical multinationals; better regulations with governmental oversight of integrated/alternative/complementary medications-practices-sales; effective oversight of food-chain(farms/imports to grocers), protections of NHS staff from assaults and abuses, Spending efficiencies, etc.

Statutory powers

9. As currently for PPI Forums but more powers of inspections—preferably unannounced for effectiveness—for all areas including clinicians, ordering/purchasing/spending efficiencies, management accounting with radical departures from current complacent auditing towards instituting the audit function as an aggressive management tool for economic optimisations in the absences of credible empirical formulae for performances measurements, eg profitability, rates of returns on capital employed and/or capital employed plus recurrent revenues within fiscals.

Relations with local health Trusts

10. This must be statutorily encouraged to counter uneconomic duplications, gaps in local provisions, and contribute better within the organogram, particularly for the specialists as well such as Mental Health, Ambulance, etc.
National coordination

11. My experience being limited to London, I suggest leaving things as they are with the present London Network of PPI Forums, and, the present reference group of The Healthcare Commission—both deficient in diversities, eg the young, and, races.

_How should LINks relate to and avoid overlap with:_

Local Authority structures including Overview and Scrutiny Committees

12. Statutorily Distinct-Separate-Autonomous with reciprocal co-options but without voting rights to avoid politicisations of LINKS. Our own OS&C here in Enfield is not value-for-money, ineffectual, patronising, and highly cosmetic.

Foundation Trust boards and Members Councils

13. I would recommend an urgent interim body comprised of Association of Local Government/Authorities, The Chartered Institute of Public Finance and Administration, NHS Executive, HM Treasury, The Confederation of British Industry, The Institute of Directors, The Trades Union Congress, Useful Non-Political Peers, a sprinkling of individuals to be selected exclusively by The Head of The Home Civil Service, must be assembled with a wide-ranging remit to introspect these and feedback their recommendations initially excluding MPs and Councillors inputs.

Inspectorates including the Healthcare Commission

14. For reasons of credibility, ethics, and protection from bullying, I would prefer a unique inspectorate outside of and not controlled by the Healthcare Commission, so, suggest within The Audit Commission.

Formal and informal complaints procedures

15. To remain as they are—Trusts must never be final arbiters for historical and obvious reasons.

_In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?_

16. Whenever deficiencies or major statistical errors of omission/commission are reported or suspected: consultations processes to be exploited should include press, radio, television, internet, central government (Health, Inland Revenue, Social Security etc), local authorities etc databases, etc.

I submit all above as an individual and would be prepared to answer The Parliamentary Health Committee questions in public if required.

**Seton During**
London Network of Public and Patient Involvement in Health Forums
[comments are made as an individual]
12 December 2007

_Evidence submitted by Ron Eskdale (PPI 43)_

I have been involved in a number of cancer groups for a several years and currently chair the Patient Partnership Forum (Central South Coast Cancer Network), In addition to my experiences as a cancer patient I have examined recent published material produced by the Department of Health and Joseph Rowntree Foundation during 2006. As you will see from the letter heading that I am interested in developing communication aids to improve efficiency in groups such as meetings.

I am prepared to answer questions should members think this would be of interest and value to them.

1. Executive Summary

1.1 I find some of the evidence produced by the Department of Health in places confusing and, reminiscent of a script for “Yes Minister”:

   eg “If we are to create a truly user-led service, centred around the needs of both individuals and communities, it is essential we create a stronger voice for patients, service users and citizens at all levels of the health and social care system”.

   I hope that operations will be still consultant led.
I would have liked to have seen some reference to the development of partnerships between patients, their carers and health professions.

1.2 The problems of user involvement are well documented in the Joseph Rowntree submission, I am not certain how the introduction of LINks will help. Some reasons are outlined below:

— As far as I know no pilot schemes have been used.
— Both Health Authorities of various kinds and Local Authorities are under financial and administrative strain and external pressures at present. This is hardly a good time to introduce change.
— Nationally designed programmes seem not always to be appropriate to differing local conditions. Good practice and administrative directives do not usually travel well.
— The questions posed on page 24 of A Stronger Local Voice reveal some most helpful key questions which really need to be answered before deciding to introduce a new system of public involvement in the NHS.

1.3 My experience suggests that before partnership groups and committees function well the following conditions need to apply:

— The host institution needs to be supportive in providing accommodation and staff where this is appropriate.
— It is essential that each group or committee has a senior health professional as a regular member of the group or committee. This person should have good contacts within the organisation and have administrative support. Who pays for this will always be a bone of contention.
— Meetings should be chaired by a person who has the necessary skills. Training of course will frequently help. However what is more important is finding the right person; to do the tasks. It can either be a patient or health professional.

2. Submitter’s Experience and Area of Expertise

2.1 Experience of chairing different types and size of meetings and conferences.
— academic meetings in Polytechnics and other Higher Education Institutions.
— Charities.

2.2 Teaching experience in management with various Institutions including the Open University as part time tutor.

3. Recommendations

3.1 Suggest the introduction of LINks is delayed until further work is carried out on the implications for NHS organisations such as hospitals and whether it can implemented in its current form.

3.2 Suggest an appropriate organisation to undertake this is the NHS Centre of Involvement at Warwick University.

Ron Eskdale
5 January 2007

Evidence submitted by Ray Evans (PPI 37)

My comments in relation to PPIF involvement are as follows:

1. The PPIF is totally independent and deals with its PCT from a patients perspective and can evaluate its findings by actually speaking to patients as distinct for example the Healthcare Commission which mainly analyses data supplied by the PCT’s and has minimal “coal face involvement”.

2. Regardless of what the Under Secretary of State as said in support of change in that PPIF’s duplicate other inspection agencies. The actual situation is that this is not the case. I am not aware of any other agency actually physically visiting doctors surgeries, health centres, or hospital wards. We actually walk “the patients pathways” with the patients and identify problems. The PPIF does not deal in conceptual patient care or “NHS wish lists”.

3. The new LINK’s Forum’s should retain statutory inspection rights.

4. The expertise of current PPIF members should be retained along with existing structure.

5. The most cost effective option would be to “bolt on” Local Authority members and single medical issue groups to the forum.

6. Funding for LINK’s should be “ring fenced” if delegated to Local Authorities.
7. There is no problem I am currently aware of in the relationship of PPIF’s with OSC’s, PCT’s and the Healthcare Commission. I think that the suggestion of “overlap” is something of a distraction. I have never encountered this problem and it has never been raised by any other forum members in my area.

8. All agencies would hopefully be striving to ensure that the best medical care is quickly and readily available regardless of which direction an agency approaches the problem.

The PPIF’s are currently the ONLY independent voluntary patient advocates within a monolithic and bureaucratic organisation. The totally replace them with other nominees from other branches of government would be to negate the mantra that the NHS should be patient led.

Ray Evans
PPI Forum for the East Riding of Yorkshire (comments are made as an individual)
20 December 2006

Evidence submitted by John Fearn (PPI 22)

There has been a marked failure on the part of the Commission for Patient & Public Involvement in Health to conduct the above procedures in a fair, just and equitable manner. Being an independent non-departmental Government body its complaints procedures are independent of the Department of Health and the Minister of State responsible for this body due to intervene when irregularities and injustices of CPPIH’s administration of the Complaints procedures are brought to attention.

The Minister of State’s attention having on four occasions, been drawn, to serious maladministration by CPPIH’s of their Complaints procedure by Bob Blizzard MP, Waveney, refused to intervene on every occasion. Reference was made to the availability of access-to the Parliamentary Ombudsman, as a final resort, but, invariably such access is denied because Para 10 of Schedule 3 of The Parliamentary Commissioner Act 1967 bars investigation of complaint regarding public service personnel matters.

Attached is a copy of the latest rejection by the Minister of State who, in the second proffers a contradiction in terms where she declines to act yet supports the conduct of CPPIH. The matter referred to should not have been regarded as a complaint, but, refusal by CPPIH to furnish membership detail of a PPI Forum Chairman, in contravention of the empowering Parliamentary Statutory Instrument, In her final paragraph the Minister advocates the need for transparent communication and public accountability.

May I take this opportunity to offer to give verbal evidence to support allegations and in any case I should wish to be present at this Session of the Select Committee’s investigation of Patient & Public Involvement in NHS.

John Fearn
4 January 2007

Evidence submitted by Barry Fineberg (PPI 15)

1. What is the purpose of patient and public involvement?

1.1 The Health and Social Care Act 2001 required all local bodies responsible for health services to be subject to local consultation, directly or through representatives, notably in their planning, but also in their development and operation.

A subsequent White Paper (2006) “Our Health, Our Care, Our Say” brought social care into focus with health, both part of a more comprehensive system closer to peoples’ homes. This later requirement throws into relief a greater reliance on public consultation in order better to define and to incorporate the detail and the diversity of local needs.

2. What form of patient and public involvement is desirable, practical, and value for money?

2.1 The Department of Health’s call for the reconfiguration of primary care looks to more local community services as a counterweight to existing hospitals in complementary functional patterns. The smaller organisational scale is implicit in its formative language referring to supports “closer to home”, “putting the patient at the centre”, or a “patient lead NHS”—the human scale.

2.2 The vision is splendid. The challenge, however, has a self-defeating complexity that needs greatly more manageable local frameworks and processes. The Department of Health makes clear the desirability of its vision. Its practicability however requires a much smaller focus, a more intimate public arena than is

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72 Not printed here.
realisable through current government forms. The necessity both to define and to enable local frames of reference at appropriate levels of need below that of existing authorities must be manifest if the confidence and the engagement of local communities in consultative dialogue is to be comfortably established. There are also implicit economies both of effort and of expenditure in local enterprise and organisation given, as far as possible, appropriate self-managing discretion.

3. **Why are existing systems for patient and public involvement being reformed after only three years?**

   3.1 The energy and dedication of Forum members in the exercise of their monitoring duties is exemplary. It is clear to me however, as a Forum member, that successful outcomes have been elusive, exhausting, and greatly incommensurate with time and effort.

   3.2 There is a sense that whilst the health management system within which the Forum has been embedded is commendably organised in its sundry parts, it is deficient in the connections between many of those parts beyond their own separate influence and control. Efforts to navigate such intricacy through supplementary liaison functions only compound that very complexity.

   3.3 Government effort for reconfiguration must therefore be a step in the right direction, providing that simpler mechanisms are now put in place to enable gradual, evolutionary change in timely and cost-effective ways. Such directives will encounter these functional resistances within current systems which must be addressed. More bite-sized units of organisation and management will instead greatly enhance the efficacy of new patterns of initiative and service at grass-root levels.

   3.4 The scope, range and effectiveness of public effort in PPIH Forums has been limited by the foregoing complexities. Participation as a consequence has been mainly reactive, to forces and factors of which there is often little foreknowledge or understanding. Efforts of Forum members to grapple with this challenge have been noble and worthy but, in my observation, barely sustainable. Though wider networking might attract greater numbers of Forum members to share this burden of responsibility, the difficulties will in my view remain intractable. The way forward must be to adopt a more proactive stance, through closer public command of the processes of planning and commissioning, as the Department urges.

4. **How should Local Involvement Networks (LINks) be designed?**

   4.1 The proposed organising principle and framework that follows gives structure, form, energy and direction to social forces. It has a scope for graduated, measurable and systematic processes of change, bringing wider economic and political forces into balance with social need. It is this local balance which government seeks to engineer and to engage, the enablement of local markets in health and welfare and their accountability to local communities. The aspiration for enhanced local democracy must be very important and carries with it a marker for change, bringing interdependent remaining services more coherently together with each other and with their political controls.

   4.2 Many citizens would identify with smaller communities more readily than with the boroughs and cities in which communities are embedded. The strategic and political purposes of the wider whole can however be better realised by acknowledging the city as the sum total of its boroughs, and the boroughs as the sum total of its local and diverse communities. The planning and delivery of public services through township networks would be found to be more responsive and more focused than to widely dispersed undifferentiated populations.

   4.3 Sets of local community may be mapped at corresponding levels of need from street and neighbourhood upwards through town centres to clustered groups at higher service and regional levels. Social mapping and its ensuing service hierarchy frame a more ordered urban structure which must be the spur for civil engagement and its mobilisation through an enhanced sense of local attachment and mutual responsibility.

   4.4 Town centre networks offer the most critical level of intervention in the hierarchies of space that make up the city. The model is organic and holistic in its scope, corresponding with natural principles of distribution and organisation in which neighbourhoods are the cellular parts of an organic whole, the township. Its nucleus, the town centre or High Street is a fixed point in a sea of infinite statistical variables, with optimal purchase in any local urban calculation, social, political or economic. Its catchment population is its community, an identifiable and measurable entity. Given public voice, the emergent community would be enabled once more to seek leverage in the local arena which is the natural market of its central place. Neighbourhoods as a modus operandi fit within such embracing frames of reference, giving them focus, direction and purpose.

   4.5 This formative critique corresponds with market principles, describing a social market system. It carries a scope for market forces to be called to social account at ascending levels in the spatial hierarchy. Its theoretical justification lies in the empirical development of Central Place Theory, a founding geographic principle.

   4.6 Town Centre Forums would be in a position to better encourage and support local service providers in formal or informal partnership with public, private, voluntary and informal sectors, perhaps in the form of a local trust. Local townships and their High Streets remain historically the natural arena for local
citizens. This contrasts with ailing High Streets, hollowed of former functions and purposes, continuing to command from their innate focal position continuing spheres of attraction and identity. The pending death of the High Street with its detriment for local trade and social enterprise is seen with regret and resignation in the face of its seeming irreversibility.

4.7 The Department of Health’s directive for Practice Based Commissioning could be a lever for change. Ensuing patterns of natural community will enable a systematic service reconfiguration at all levels of need. Primary clusters for health, welfare, social and other supports may then be focused jointly with local GPs, pharmacists, dentists and opticians around their High Streets. This common organisational format offers a whole, the sum of which is greater than its parts. There is scope here for fine-tuning to bring normally disparate local provision into a convergent whole, breathing new life into local community.

4.8 This impulse for local engagement may however be no more than a passing phase; a merely transient set of aspirations, unless Government statements of intention to power such ambition with local budgets is made tangible and real, giving local people influence, leverage, and ultimately greater control. For forty years, government intervention in deprived city areas has mostly failed through poor targeting and lack of congruence between agencies but, most critically, because of their limited nature and inevitable transience. There is a scope in pending reconfiguration to reinset the local dimension, to endorse its former significance more comprehensively in all mainstream programmes, so that locally targeted expenditures may then have more focussed and lasting impact. This potential will, I am confident, attract once again a public engagement in political life. Perhaps three quarters of health and welfare expenditure is intended for local communities. Local budgets will however engage local publics greatly more than customary participatory and consultative processes if they promise “real money”, in place of what many have felt were but token exercises.

4.9 In acknowledging the natural clustering of GPs and allied health and welfare services around all our town centres, there is real leverage for radical change in the adoption of that reality as the natural focus and the natural model, a catalyst for a revived local economy. Current imperatives for change are a window of opportunity which, in the added context of the pending Local Government White Paper must be seized.

4.10 There is here a scope and a context making it possible to better engage all aspects of local governance and management through a more coherent and common organisational format and process, and through mutual compatibility. Recent announcements on numbers, costs and programmes on new community hospitals, clinics and complementary support facilities do not appear to indicate what consultative process, if any, has informed these choices. To what extent does a demonstrable local need shape these decisions? Do they reflect prior understandings with local health authorities, or do they accord instead with a one size fits all formula which cannot be locally scrutinised? There is a concern that terms of reference and criteria which might inform such decisions should have the greatest regard for the contextual framework of these provisions, closely reflecting different levels of need and natural geographic catchments.

4.11 There might be no generally agreed set of organisational principles to better enable this process. In the interests of better governance, efficiency, equity and coherence however, action-research might therefore be urgently needed into the factors and methods by which such rationales may be established in the field.

4.12 The foregoing describes social and spatial criteria for the design of local networks reflecting the professional background of the author. Its spatial critique, its clusters and hierarchies, is rooted in organic concepts of ordered distributions and controls, and its perception of natural community through catchment populations. The Committee does however look also to factors in terms of reference is remit, membership, appointment, funding, powers, and relations with Primary Care Trusts. The proffered network design principle is offered however as a sine qua non for organisational coherence and a precondition for manageable change of such magnitude and complexity. It is not in itself a policy, but rather a framework for policy.

4.13 Existing forums have sought to be absorbed within new networks in order to retain their experience and skills, for which a necessary evolutionary transformation should be possible. Forum membership and capacity can be greatly expanded through possibly informal sets of elected complementary forums at township levels and above; underpinning and consolidating the role of councillors and representatives with health, local and other authorities in policy formulation and programming.

4.14 Economies of smaller scale must flow from such reductions in complexity, enabling more responsive and mutually coordinated local services. Given appropriate advice, guidelines and seed funding, a newly reinforced public interest can be encouraged and harnessed through self-defining and self-managing processes. Transitional arrangements might be speedily effective through enabling and encouraging the initial formation of networks by voluntary action in the interim. Subsequent legislative endorsement may then be shaped by the evidence and example of working sets of local forums put in place informally “in the field”.

4.15 Citizen mobilisation of such magnitude and ambition may only be realised however on the promise by Government to allocate specific funding packages to local communities, albeit held on trust initially at higher levels. Management of existing authorities may perhaps be modified correspondingly through matching small-area information systems. Such fine tuning will rest in turn on social audits derived from census and other information, annually updated, on a per-capita basis for local budgets, and as a more tangible subject for local interest, scrutiny and deliberation—the essential catalyst for public engagement.
4.16 This outline genesis must however rest on a greater degree of mutual trust enabled and encouraged through flexible, informal and discretionary mechanisms, free of the more prescriptive regulation that encumbers the better performance of existing local authorities. A reducing complexity may also be gained by those authorities through disaggregating existing data and information for local populations. The total of their more detailed needs may then be brought more clearly into balance with higher level services and functions, a budgeting framework.

4.17 Local arenas will bring together social and welfare agencies whose cross disciplinary coordination is often difficult, and sometimes tragically elusive, having to cross multiple boundaries of concern and responsibility. These agencies would be enabled more closely to consult, to share and compare information, and to act in more timely ways successfully together through more locally common focus and boundaries.

4.18 This scenario is neither definitive nor exhaustive. It gives only a token indication and a flavour of more mutually trusting and engaging cultures of local politics and local service which should be possible, and more greatly effective. It seeks to develop the detail set down in the Double Devolution and Neighbourhoods Agenda of David Milliband, former Minister in the ODPM, presented to the expert panel meeting on 6 April 2006 by Mark Rickard of the former ODPM and now of the Department of Community and Local Government. That panel, in its recommendations to the Department of Health for the creation of local networks has prompted this evidence for their configuration and establishment.

Conclusion

The foregoing seeks to address many of the questions in the Committee’s terms of reference from a particular point of view, that of the redesign of existing structures in Health and Social Service management systems and their political and administrative frameworks. There is however an underlying imperative here for reducing the size and scale of administrative units to enhance their transparency, manageability and accountability.

Among considerations which must flow from this premise will be objections to yet further layers of government on the grounds of inevitably greater cost. Cogent argument is however to be made and there is evidence in favour of significant economies of smaller scale in the more ordered provision of public and personal services through reductions of perhaps 90% or more in their organisational complexity.

It is also my further observation that reductions in organisational complexity through smaller scale are likely to make possible material improvements in the control of cross-infection and of epidemics. More widely dispersed patterns of lesser community health provision will help curtail excessive movement now generated within and between greater hospital or clinical concentrations, both pedestrian and vehicular.

These and other matters beyond the reach of this initial submission will require further consideration and should also be seen in the context of health and welfare matters to be incorporated in the pending White Paper on Local Government reform. I trust the Committee finds much that is useful here and much food for thought. I hope it will wish to follow up this reasoning, with its implications, and shall be happy to answer its queries at open session if the Committee so wishes.

Barry Fineberg
15 January 2007

The author is a member of Barnet Primary Care Trust PPIH Forum. Members of the forum view the foregoing issues to be largely outside their remit and have given no opinion other than to draw the attention of the PCT to them.

Evidence submitted by Tony Fletcher, Scout Enterprises (PPI 60)

Over the last two years we have operated in an atmosphere of uncertainty about the future of PPIF’s, and the wider purpose of Patient and Public involvement. I have witnessed an array of ideas and possible solutions from the DoH, none of which have yet to come to fruition.

The level of details about how Local Involvement Networks (LINks) will operate (and be judged to be successful) seems to be rather vague. Membership is intended to cut across a wide spectrum of areas, and may vary from individual members to those with organisational interests. In my experience of PPIFs, governance arrangements have been key to underpinning their success, along with a clear and achievable work plan. Under the current proposals (and I apologise for paraphrasing this description of partnership) it seems to be the indefinable in pursuit of the unachievable.

As you will see from the attached information provided there are still many questions arising from the proposals for LINks. However I do feel FSOs are uniquely placed to assist in overcoming these and making any new system a success.

I sincerely hope that your inquiry will be able to deliver its terms of reference, and that Patient and Public involvement in Health will once again be seen to offer good value for money to the taxpayer.
1. Summary

1.1 In March 2005 the DoH published its response to the consultation exercise on the Future support arrangements for PPI in Health (gateway ref: 4629). Within it were very clear ideas for the future direction of Patient Forums after the abolition of CPPIH. The NHS Appointments Commission was to recruit members and in particular appoint Chairs. FSO contracts were to be awarded on a regional basis and Forums were going to be reconfigured into PCT areas. It even set out a timetable for the process to follow from May 2005 to August 2006.

1.2 However by the time the “expert panel” arrived in February 2006 the whole document appears to have been shelved, and we are now facing nowhere near the level of detail previously shown. It feels like any lessons learnt from the abolition of Community Health Council’s (CHC’s) have been quickly forgotten.

1.3 The DoH need to recognise that Forum Support Organisations are uniquely placed to support LINks, and continue the development of a Stronger Local Patients Voice. They have the relevant experience and potential to guide LINks through their developmental stages into becoming successful organisations.

2. Introduction

2.1 I am a Manager of a Forum Support Organisation, which has been providing support to 19 Patient Forums across the South West Region since September 2003.

2.2 We set up and ran these Forums in four contract areas (Cornwall, Plymouth, Gloucestershire and Bristol) with a range of skilled staff from both NHS and other professional backgrounds. I set out to employ such people as I felt a combination of experience would prove valuable in performing a support role. This has proved its worth over the last three years and I feel has contributed significantly to our success as an FSO.

3. Information for the Committee

3.1 FSO’s provide and maintain the direct support for Forum members. This support is now increasing as the result of CPPIH greatly reducing it’s staffing complement. Governance issues are now expected to be dealt with locally by FSO staff rather than previously by CPPIH staff. Whilst this may help develop our expertise, it presents a fundamental shift in our relationship with the members.

3.2 PPIF members receive a “postcode lottery” of support due to the original process of competitive tendering. All FSO’s now having a national service specification yet receive very different amounts of money to perform those duties. I welcome the idea of having a transparent process that allocates money to an area on a clear formula, with the emphasis on the “Host” organisation to prove its added value as an established organisation.

3.3 What is the financial benefit to the tax payer of the new system? Given the costs of dismantling CHC’s, setting up CPPIH (and now running that down), Parliamentary time for setting up LINks, transition costs etc, these must be considerable. It is the DoH’s stated aim that there must be evidence that their policy’s will improve the delivery of Health and Social care. Where is the evidence to say PPIF’s have failed?

3.4 FSOs have built up the relevant knowledge and structures that should be used for future support of LINks. Any loss of this expertise will severely curtail the development of LINks and presumably the Governments desire to strengthen the Patients voice.

3.5 Can a “Host” organisation have the relevant infrastructure to support LINks at a local level? Until recently (2005) the DoH was advocating regional contracts for FSO’s on a similar model offered to ICAS providers. The tension in the new system will be the ability to provide a service that can reflect local knowledge and expertise, with an infrastructure to support a wide range of functions.

3.6 We have been through extensive performance monitoring exercises but have never been asked to monitor Forums performance. If LINks are to be seen to be successful by patients and public they will need to have well publicised critical success factors. Who (and how) will performance manage LINks?

3.7 CPPIH are now the largest FSO with their in-house teams, which is testament to the failure of numerous FSO’s to provide an acceptable level of support. It is also indicative of a systems failure that would have ensured they were better prepared to support members correctly from the out set. By setting out a clear service specification for the new Host organisations which builds on the best FSO performance, this could be prevented.

3.8 FSO tenders are now extremely short term (the latest being six months) and so it’s very difficult to recruit and retain staff. This will never enable support organisations to provide a consistent and professional service to its membership.
4. Recommendations

4.1 In order for LINks to be professionally supported there needs to be absolute clarity about the roles and responsibilities of Host staff.

4.2 There needs to be reliable financial information about the budget available and clear lines of responsibility for its expenditure.

4.3 A clear governance structure needs to exist for each LINk to ensure a fair and transparent approach is adopted and maintained across the country.

4.4 Existing skills/staff should not be lost to future Host organisations due to the inability to plan for a proper transition, and allow continuity across the two systems.

4.5 Contracts will need to be of at least three years duration with an agreed inflationary uplift.

Tony Fletcher
Forum Support Organisation Contract Manager
Scout Enterprises
9 January 2007

Evidence submitted by Trevor Gash (PPI 146)

I am submitting this response as an individual, but notify you that I am Chairman of the PPI Forum for the Luton and Dunstable Hospital.

An issue, which is not offered for consideration is the proposed title for the new organisations. At a recent “Getting ready for LINks” event I tested the matter with various Local authority, FSO, NHS, voluntary organisation and Forum colleagues and received a unanimous agreement that it follows the pattern of both preceding organisations in conveying little or nothing of the role or purpose to the public.

1. What is the purpose of patient and public involvement?

1.1 It should provide an effective replacement in public services of the customer power exercised through purchasing choice in a free market.

1.2 It should represent, as far as practically possible, the balanced view of the population within an area and not an assembly of the views of special interest groups.

1.3 It should be a voice for patients in all matters of concern other than issues of individual complaint.

2. What form of patient and public involvement is desirable, practical and offers good value for money?

2.1 Volunteers recruited after widespread, clear and honest publicity working within a professionally managed organisation under uniform systems and codes of practice.

2.2 Organisations with which commissioners and providers are obliged to engage in a meaningful way in clearly understood areas of involvement.

3. Why are existing systems for patient and public involvement being reformed after only three years?

3.1 Because of substantial mismanagement by Government/Department of Health from the outset evidenced by decision to abolish Commission just five months after setup of Forums and inability of DoH to understand frontline reality, most clearly indicated by John Reid statement relating to MRSA policy.

3.2 Absence of material and productive input from the Director of Patient and Public Involvement in Health.

3.3 Absence of compulsion [on a level of importance equivalent to targeted functions] on NHS Units to fully and actively engage with Forums.

3.4 Confusion with regard to the roles of other organisations in the matter of representation.

4. How should LINks be designed, including

Remit and level of independence

4.1.1 If the declared aim of an integrated approach is to be achieved, then remit should include all areas of healthcare and healthcare related social care, even if, direct involvement is proscribed as is claimed to be for valid reasons in regard to Children’s Trusts, so as to avoid failures at margins or interfaces.

4.1.2 Whatever associations Members have, LINks should be totally independent of NHS, local authorities, voluntary organisations and special interest groups.
Membership and appointments

4.2.2 Membership should be confined to individuals, it is totally unacceptable for organisations to be members.

4.2.3 The matter of CRB checking in relation to the very necessary right of entry and possible contact with vulnerable individuals, suggests that two classes of membership should be available so that those who chose not to be involved in “monitoring” are able to do so, but clearly identified.

Funding and support

4.3.1 Funding must be on a uniform basis, achieved by whatever bureaucratic, but transparent process is available, but a review should be undertaken to establish the appropriateness of adjusting local funding within a national framework to account for matters such as the additional costs involved in translation work in areas of high ethnic diversity/recent immigration.

4.3.2 Support organisations should have to demonstrate a sound basic understanding of the structures, systems etc with which members have to engage.

Areas of focus

4.4 No comment

Statutory powers

4.5.1 The right of entry has apparently been accepted. It is essential.

4.5.2 All commissioners and providers should be compelled to operate under an obligation of ongoing informal consultation as well as substantial change and major public consultation rules.

4.5.3 Guidance/rules should make it clear that normal route of referral to DoH or Monitor should be via Overview and Scrutiny, but option should be available for time critical issues to be referred directly.

Relations with local health Trusts

4.6.1 Obligations to achieve a “social contract” with Trusts should be incorporated, forcing Trusts to fully engage with LINks and obliging LINks to behave considerately, constructively and consistently with Trusts.

4.6.2 The Health Select Committee should review the DoH policy in this area. Inverted logic seems to be applied in regard to the impact of “Choice”. Specialist Hospitals with national catchments and Ambulance and Mental Health Trusts with catchments crossing local authority boundaries seem ill-served.

National coordination

4.7.1 Unlike a number of Forum Members, I do not perceive a need for a significant organisation, but a small secretariat able to collate input, identify nationally shared significant concerns, facilitate liaison and report to DoH or Monitor or issue Press Releases on a national basis on such issues could be valuable.

4.7.2 KMS has been a cumbersome disaster, but a national website within which individual LINks would have pages reached via a search on the homepage or direct keying [eg links.org/luton] plus a site purely accessible to LINks for seeking those with similar experience for example administered by the Resource Centre would be very valuable.

5. How should LINks relate to and avoid overlap with

Local Authority structures including Overview and Scrutiny Committees
Foundation Trust boards and Members Councils
Inspectorates including the Healthcare Commission

5.1.1 The roles appear distinct:

<table>
<thead>
<tr>
<th>Role</th>
<th>Description</th>
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<tbody>
<tr>
<td>OSC—review of substantial changes</td>
<td>Trust Boards &amp; Members Councils—service delivery</td>
</tr>
<tr>
<td></td>
<td>Inspectorates—achievement of professional standards</td>
</tr>
<tr>
<td></td>
<td>Local authorities &amp; PCTs—adequate provision of care</td>
</tr>
<tr>
<td></td>
<td>LINks—representation of public interests/concerns</td>
</tr>
</tbody>
</table>

So long as each is charged with recognising and respecting the roles of the others and obliged to work cooperatively the matter should be clear.
5.1.2 There is no mention here or in the “stronger local voice” procedure of the patient focus/representative etc. groups established by GP practices and Hospitals. Since these are not independent they should be seen as valuable assistance to the provider and not adequate discharge of PPI responsibilities. They have been a good option for those not wishing to take on the more arduous responsibilities of Forums and may offer recruitment opportunities as indicated in 4.2.3. It is their role that needs definition in NHS guidance or in legislation.

Formal and informal complaints procedures

5.2.1 The starting point should be the NHS complaints procedure, which fails patients in a significant way. Patients should be able and encouraged to make “comments” about matters good and bad. The system should make it easy for this to be done at the time of treatment/care or later. Where individual case facts are not relevant matters should be pursued on anonymous basis. Patients should be made aware of LINks and given the opportunity to pass details [anonymously if required] for the possible future benefit of others.

Internally, adverse comments should be given equal status for statistical and review purposes as complaints. Formal complaints should be distinguished only for procedural purposes. All “complaints” should be reported anonymously in a statistical analysis that is adequate enough to give a reasonable picture of area and type of complaint and response time. The report should be made regularly to the appropriate LINK.

6. In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

6.1.1 The matter of significant or substantial is well understood at the highest level in the NHS, but not apparently in some areas, if proper dissemination of the principle takes place, the first question is answered. The form should always be—for engagement at the earliest practical opportunity, with communication in plain English in as brief a manner as reasonably describes the issues. At that time or shortly thereafter, supporting facts, opinions, statistics etc. should be provided. Where it is evident that consensus exists opportunities to curtail procedures should be available. All authorities should be encouraged to explore more enterprising ways of notifying the public.

Trevor Gash
Chair, Luton and Dunstable Hospital PPI Forum (comments are made as an individual)
January 2006

Evidence submitted by Gerald Gilbert (PPI 138)

SUMMARY

1. This submission to the Health Select Committee is based on many years’ working voluntarily on healthcare issues. Two outstanding experiences during this time are being asked by hospital staff to draw management attention to a significant issue that they themselves could not, as they were either not receptive to, or available for, a frank discussion; and raising issues unprompted at meetings that staff felt unable to raise themselves, but were greeted with nods or wry smiles around the table. From this wide and varied background, a number of observations and comments can be made. These have been used in developing answers to the specific questions that the Select Committee has raised.

2. A basic problem appears to have been a failure, either to comprehend the complexity of PPIH, or to address it effectively. This seems to have been recognised rather belatedly, with talk of several hundred people becoming involved in a large LINks area. The first need for tackling complexity is for a single and clear objective to be understood, agreed, and committed to by all parties. Even then the message has to be kept as a continually reminder to all. A number of options for action may be considered and evaluated, and the most advantageous adopted. However careful this preparatory work has been carried out, some problems will inevitably arise. When this happens, it is essential to analyse the reasons and to correct them if possible. If correction is not possible, then one has to stop digging a bigger hole. This entails going back and reviewing the case for the next best option. It is not sensible to rush out and buy the latest model (which may be even worse than the current one). Good planning is also required. From a broad overview, it is necessary to drill down into detail, and then re-surface to check against the initial assumptions. It must not be assumed that the details can be made to fit without checking. Overall, the person in charge has to exhibit and encourage a determination to succeed, with difficulties and risks being also assessed as opportunities. This level of detail is the key to PPI. Local Implementation Teams (LITs), already in situ in most areas and covering many aspects of healthcare, are the venue of analysing problems and finding solutions. But they do need the right germination conditions and input from patients, carers or their support groups.
3. Arising from the above failing, many other mistakes have been made. The role of the Forums was promoted as go-it-alone, without recognition of important contribution to be made by so many other individuals and local organisations, with the need for facilitation, coordination and encouragement. Members were selected on a different basis, and the key role (and time and effort required) of the Chairman not defined or recognised. The responsibility of Forums has been only seen from the top down, which should only apply direct to the Department of Health for financial accountability and good governance, not to any other body or Commission; whereas Forums should be principally accountable to patients and public. The task requires local professional staff, selected by the NHS Appointments Board, for the top-down responsibility, with experienced support staff also based locally (an aspect that the Select Committee expects and acknowledges from its own staff). With Forums in such disarray it should not have been surprising that many Trusts have largely overlooked the potential benefits that they should have derived from well-informed constructive dialogue with them.

4. Although the Select Committee has not asked directly for comments on the Local Government Bill, its imminent passage through the House of Commons does make this most relevant. It is quite bizarre that a healthcare matter, affecting the NHS even more than Social Services, should be included towards the end of a large Bill on local government. The only valid reason for this is the need to regularise the position of the PPI Commission, that the Government announced was to be abolished, back in 2004. There may be another agenda, but it should not be on grounds such as economy of scale, or forcing forward the move to play down the burden and responsibility for healthcare from the NHS as the major player, onto the Social Services and the voluntary sector. How LINks might work in practice has yet to be seen. From discussions, it has become apparent that the “early adaptors” and pilot LINk groups are going to have to feel their way, without much in the way of guidance from CPPIH or any other body. It would be premature, fool-hardy and bad management practice to introduce legislation to remove Forums until their successors have been seen to work. I have attempted another definition of “health economy area”. There are signs that the larger PCTs are already setting up sub-structures with similar boundaries. (So much for the economy of scale).

5. The problems and challenges would have been a major obstacle in any event, but the situation has aggravated by two other significant factors; financial pressures and the pace of change. The task would have been demanding even in a relatively stable environment. Many concerns of patients and carers would have existed, since most problems arise at the interfaces between two systems. Healthcare examples include discharge from hospital, need assessment and care packages, which overlap the boundary between the NHS and Social Services, as already considered by the LITs. Continual change has meant that attention was directed almost exclusively towards consultations and the consequences of re-configurations rather than ongoing problem areas.

CREDENTIALS

6. I have been actively involved in healthcare matters for the past twenty years or so, from working with the then Member of Parliament to get a local community hospital rebuilt, then leading a public campaign to discourage the Authority from closing one of its two wards shortly afterwards, and organising major fund-raising events over many years during which time these raised some £100,000. I served as a Regional Officer of the National Association of Hospital Friends, and was invited to join a Community Health Committee. I was a member of a PPI Forum for a time, and am a member of the Community Hospitals Association. I am not a member of any political party, and this submission is made solely on a personal basis.

BACKGROUND TO SUBMISSION

7. With my personal interest and experience, I have been able attend and participated in numerous local, regional and national conferences and other meetings on this subject. Examples include the London National Launch of the Commission for PPIH, a meeting of Forum members convened by the Surrey & Sussex strategic Health Authority, and the Opinion Leader Research conferences on the options arising from the Government decision to dismantle CPPIH. For these I have often submitted a contribution for discussion, and afterwards prepared notes and circulated them amongst a network of other enthusiasts and contacts.

8. Recently I have summarised much of my thinking into three documents: The NHS Challenge—The Case for a Fresh Approach, Making the Mission Possible, and LINks and the Department of Health. These have been used as the basis for answering in Section 4 the questions posed by the Select Committee. Only the last of these three documents has been included with my submission as a reference document. It is little changed from the original dated 27 January 2005, which was sent shortly afterwards to Mr Meredith Vivian, Head of PPI at the DoH. His reply dated February 16 was rather interesting. “Thanks for your comments and attachments. I do find your comments most helpful and thought-provoking. Re the transition board. What we have in place is a programme board comprising those organisations which have specific responsibilities around the delivery of PPI arrangements. It is a board to oversee the strategic direction of how we implement the ALB Review—it is not there to provide insight into the operational aspects or to oversee the transition from A to B. We do have plans to ensure that on all the work streams to deliver the ALB Review we have forum member input and I am sure you will hear more about these in due course. Re the timescale issue. Without primary legislation there is very little we can do to speed matters up. The CPPIH
remains in place to deliver its statutory functions and until another body has those functions they cannot be handed over. What we can do in the meantime is make sure that we develop as effective a set of new arrangements as is possible—also making sure there is enough time to put them in place prior to CPPIH abolition. I know this will mean that in the short term we may have to make the best of less than ideal arrangements but I am sure we are wise to take our time and get the best long-term system in place. Thanks again for your comments, kind regards, Meredith Vivian, Head, Patient and Public Involvement”.

This provides an interesting backdrop to the lack of progress in the past two years.

9. In addition to the document referred to above, I have attached “Post-Forum Teams and the Chairman Role”. This was prepared in response to a request for suggestions on how to appoint a chairman for a PCT Forum, recently enlarged to match the PCT mergers. This outlines one way of involving many more people in the PPI experience, as the DoH itself is now suggesting. The LIT approach has been used when setting up teams to discuss and then make plans and recommendations for each of the Government standards of the National Service Framework for Older People. A similar approach would be helpful in addressing the National Programme Budget Project, which considers the treatment of 21 major diseases as the realistic targets to be met.

10. I know that the Surrey 50+ Group (formerly Better Government for Older People) has some 450 members who would like to play some part; and the former West Surrey Health Authority had a database of 600 local organisations (mainly voluntary) with a similar interest. This illustrates both the complexity of the challenge, and the source of willing helpers.

11. I am also aware of the DoH’s July 2006 publication Health Reform in England—PP Engagement in Commissioning, and the Conservative Party’s proposal Health Watch. Both use a new expression “engagement”. I refer to verbal transformation later, but for the present will use the Government proposed expression LINks, which also appears in the Select Committee’s terms of reference, although this is not yet on the statute book.

12. The Committee’s terms of reference also refer to the NHS only. I accept the Government’s latest view that the subject is wider than that, covering as it does healthcare provided by the Social Services, another clear responsibility of the DoH. The LINks proposal actually goes much further. It considers the “locality” as the geographical area covered by a local authority with social service responsibilities. This may be one way of resolving the “co-terminosity” dilemma, but also illustrates how a concept such as Bringing the NHS closer to Home develops, first into Care in the Community, and then an attrition of the role of acute and community hospitals, by removing PPIH from the NHS agenda, and placing the burden and responsibility for healthcare on the Social Services and the voluntary sector. My objection to such gradual easing in new meanings does not imply any opposition to progress, such as the concept of super A & E departments, but I do consider that changes made for scarcely-concealed financial reasons may not be in the public interest, which is at the heart of PPI.

13. The Select Committee’s report on NHS Finances included numerous references in the evidence to “local area”, but I can find no definition of the expression. I believe that an essential component in the overall healthcare system still is secondary hospital care, in what used to be referred to as district or general hospitals (and intermediate care provided by PCTs in community hospitals). From this, I would define a local health economy as being centred on a NHS Hospital Trust, with one or more hospitals, or a Foundation Trust hospital, serving the same purpose; funded by one or more PCTs; working in conjunction with Social Services covering the same geographical area; and supported by some part of a Mental Health Partnership and Ambulance Service Trust. This has proved to be a practical and manageable concept in the past, and I see no reason for changing it on the grounds such as economy of scale. It has been used in considered detailed responses to the Select Committee’s questions, in Section 4.

RESPONSE TO THE COMMITTEE’S QUESTIONS

Purpose of PPI

14. The single underlying concept of PPI is that Healthcare clients; patients, carers and voluntary healthcare organisations representing them; must have their views taken into account at all times. It calls for a sound working relationship between the “system” and clients, with the emphasis on outcomes rather than processes.

The desirable outcomes are:

(a) Meeting the needs (not wants) of clients.
(b) Providing a service with value-for-money.
(c) Making more effective the care pathways already in place, as well as gradually introducing innovations.
(d) Ensuring that disturbances do not cause self-destruction, but are continually reduced and smoothed out.
15. These outcomes are an embodiment of democracy, and also, arising from the Bristol Infirmary investigation and the Kennedy report, were an essential part (Section 11) of the 2001 Health and Social Care Act, which itself related to the Overview and Scrutiny duties required by Section 38 of the 2000 Local Government Act.

What form of PPI is desirable, practical and offers good value for money?

16. A number of words and expressions have been used to define PPI; involvement, consultation, and engagement, significant (coupled with “changes”). The fundamental requirement is for the client representative(s) to have a seat at the LIT (Local Implementation Team) table as an active and constructive participant with the opportunity to contribute, whenever problems encountered with existing procedures need to be resolved, and when new plans and procedures are being considered.

Why are existing systems being reformed after only three years?

17(a) The reason is that clearly they are not working well. The Government recognised this early on, with the decision to abolish the Commission for PPIH. To discuss how this situation came about, it is necessary to look deeper. It is suggested that the complexity of the task was not appreciated, that planning was superficial, and the corrective action adopted was wrong.

(b) When dealing with complexity, it is essential for a careful path to be trod. The first need is for a clear objective to be understood, agreed, and committed to by all parties, who must sign up for it. Even then the message has to be kept as a continual reminder. This means keeping an eye on the ball, and avoiding distractions (such as blind alleys, red herrings, and other agendas creeping in).

(c) Good planning is also required. From a broad overview, it is necessary to drill down into detail, and then re-surface to check against the initial assumptions. It must not be assumed that the details can be made to fit without checking.

(d) A number of options for action may be considered and evaluated, and the most advantageous adopted. However carefully this preparatory work has been carried out, some problems will inevitably arise. When this happens, it is essential to analyse the reasons and correct them if possible. If correction is not possible, then one has to stop digging a bigger hole. This entails going back to the drawing board, and reviewing the case for the next best option. It is not a good idea to rush out and buy the latest model, which may be even worse than the current one.

(e) How the above might have been applied to PPIH? It is clear that the purpose and objective was not clearly defined and understood, and that attention was concentrated on organisation not desired outcomes, and on changes in facilities and systems. It is not surprising that a number of serious obstacles were encountered. Obstacles can be seen in a certain amount of open or hidden resistance by some NHS managers and clinicians in response to a perceived challenge to their authority (and probably within the DoH itself). Of the two, hidden resistance is the more difficult to counter, often dressed up with spin. Over recent years, the pressures on managers have been great, with new targets, organisation changes, advancing technology and clinical protocols, workload and time. A major problem for many has been Finance. Finance in the NHS has been discussed elsewhere, and at length. It should have been approached on a better basis (as the Select Committee itself has recognised), kept in proportion, and never have been allowed to take centre-stage during PPI discussions.

(f) The Commission itself produced detailed but not very helpful procedures. It did not attempt to define the Forum members’ role. Suitability of new members was assessed from criminal records and looking at an individual’s areas of interest and concern, instead of their ability to contribute and work in a team to a common agenda. The emphasis has been on doing the work themselves, rather than as proactive facilitators.

(g) With Forums themselves, in such disarray, it is no wonder that many Trusts (and Overview & Scrutiny Committees) have found little time to take them seriously.

How should LINks be designed in relation to

Remit and level of independence

18. The remit of a LINk should be to fulfil the single purpose of PPI, ensuring that healthcare professionals have the benefit of a wide-ranging input from both patients and the public into discussions on problems encountered, and solutions to be considered. LINks should be enabled to carry out this role without direction or guidance from any Government department or Commission. They should be accountable only to the Department of Health for good governance and financial control, through a national and regional management structure and (non-executive) professional staff, the latter appointed by the NHS Appointments Board.
Membership and appointments

19. LINks members should be appointed by local voluntary healthcare support organisations, solely on the criteria of their ability and willingness to work as a team towards a common objective, calling for an appreciation of the need to involve, encourage, and co-ordinate, the activities of the many other individuals on numerous working teams (LITs) within their locality; and to facilitate this work, by dialogue with healthcare providers and commissioners. A LINks team should consist of a small number of members, say 20 maximum for the largest, with an Executive Committee, a Chairman and Vice-Chairman, selected by the members from amongst themselves.

Funding and support

20. Funding should be received from the DoH, as indicated under 18 above. Professional and experienced administrative support is required at a local level, with administrative staff being recruited and managed by the professionals appointed as 18, with appointments being subject to review by the members.

Area of focus

21. The geographical area should correspond to the local health economy area, rather than be set by any other boundaries. The role of LINks and its members is very large, and concentration on key aspects is essential. Important local issues such as public health, healthy living and preventative measures must not be allowed to divert attention from the provision of healthcare. Other valid concerns are fringe matters that are adequately covered by other existing arrangements and management procedures. These include complaints procedures, and routine inspection rights.

Statutory powers

22. LINks require little in the way of statutory powers. Relations with local health Trusts is discussed below, and right of appeal on disputes should only be available to Overview and Scrutiny Committees and the LINk Regional and National executive bodies.

Relations with local health Trusts

23. The LINks Chairman or his nominated delegate should have open-door access rights to all Trust non-executive board members and to the Chief Executive. This applies to Primary Care Trusts, NHS Trusts and NHS Foundation Trusts, but not to any independent providers. He should also have a speaking (non-voting) seat at all public meetings of the Trust. LINks should hold (say) quarterly meetings in public, to give an account of its own work and plans, and at which all Trusts should be required to send an authorised representative to provide any necessary explanation of written answers to previously notified questions, and to give a brief report on matters judged to be of interest to LINks and the public.

National coordination

24. Links will need a national and regional management structure to simplify and make more manageable the responsibilities outlined above to the Department of Health for good governance and financial control. They will also need higher-level support for taking to the Secretary of State any matters that they are unable to resolve with the Overview & Scrutiny Committee, and to lobby national voluntary sector organisations. Election to these bodies, and the case for all having an executive committee have been discussed elsewhere, and are not important at this stage.

How should LINks relate to, and avoid overlap with

Local Authorities and Overview & Scrutiny Committees

25. LINks relationship to both Local Authorities and Overview & Scrutiny Committees (OSCs) should be limited to being a comprehensive source of detailed experience and knowledge on all PPI matters. OSCs should be able to call upon LINks for reports needed to undertake both elements of their responsibilities. It seems that at present, Councillors are hard-pressed to undertake this work, in addition to their other duties to electorates. They then have to rely on evidence submitted by the Trusts, and on Health Advisers, who may have an extensive experience within the NHS (which gives a certain amount of bias to their judgement). Some OSCs have been unable to do more than scrutinise Trust’s proposals, and not any longer-term overview activities. LINks should make available information to local authorities based on work already undertaken, but should not be required to undertake any additional tasks.
Foundation Trust Boards and Members Council

26. Relationships to Foundation Trusts and their boards should be the same as stated above for all other NHS providers. These Trusts receive revenue funding from the NHS via PCTs, and should be as accountable for PPI as all other NHS bodies.

Inspectorates including Healthcare Commission

27. LINks must be allowed to carry out their own tasks and responsibilities without being expected to undertake extra work for other organisations. Their own work has to be put in the public domain, and so be available for all.

Formal and informal complaints procedures

28. Individual problems that arise in hospitals or elsewhere within NHS bodies should be taken up directly between the parties involved. Existing arrangements (PALS, and for matters that cannot be resolved at that level, ICAS) should be satisfactory, and outside PPI activities. One desirable feature is that both PALs and ICAS should submit periodic summary statistical reports to LINks, so that any significant trends can be picked up.

Circumstances calling for, and form of, any wider public consultation

29. If PPI were set up as outlined in this submission, there would be little need for consultations on reconfigurations. At present these are very expensive and time-consuming for Trust staff and management, and stakeholders alike. Trusts would still have to make public announcement of all proposed changes to service provision. OSCs would invite LINks and the Trust(s) to comment, and then, also taking into account any public representations made directly to it, decide if a public enquiry was warranted. If so, the OSC would conduct this along established lines. The LINks could refer matters with which it was not satisfied to its Regional management, who would attempt to resolve with the OSC, and if not successful, refer it to the Secretary of State.

Gerald Gilbert
January 2007

Annex

POST-FORUM PPI TEAMS AND THE CHAIRMAN ROLE

Different names are now being given or proposed by different parties for PPI Forums, but the underlying principle was clearly embodied in the Health & Social Care Act, 2001, and as explained very fully in subsequent Department of Health publications, such as “Patient and Public Involvement in Health”, April 2004. The Act introduced a feature that was claimed would “make Forums more powerful than Community Health Councils”, since patients and the public were to be INVOLVED in the decision-making process, with a seat at the table and a voice to be listened to when the pros and cons of options were being discussed. This would be enhanced by Forums having a non-executive member on the Trust Board, as distinct from the CHC right to have a speaking, but non-voting, role at the Board’s public meetings. The right to refer disputes that could not be resolved locally was withdrawn by the Act and replaced on the understanding that Overview and Scrutiny Committees would draw heavily on the Forum’s detailed work (and so be able to judge the merits of the case presented to them alongside the submissions of the Trust). Forums would also be supported administratively by not-for-profit organisations instead of having their own professional staff. Although the Chief Officers of these were appointed by the Department of Health and all the staff were employed by the local Health Authority, they did have a degree of independence strengthened by their close working arrangements with CHC members. The Chief Officers networked with others in the area, and had the general and legal support of a National Association, but the latter was abolished with the CHCs. The staff, often part-time, usually had extensive healthcare backgrounds. Without trying to re-invent CHCs, it is worth noting that they related to the “local healthcare area” and not just one Primary Care Group, as the PC Trusts were then known. They considered matters in which the local hospitals, mental health, Social Services and ambulance services were concerned, and representatives of these were all invited and expected to attend and contribute to CHC public meetings.

None of the fond hopes of 2001 have actually come about successfully, for various reasons. The attitude of the Department of Health has been ambivalent, and the role adopted by CPPIH unhelpful (to put it mildly), including in not actively following up the proposal for Forums for regional and national representative and coordination bodies The Healthcare Commission has not played an active role yet, apart from asking Forums to participate in more visits to healthcare establishments. (In January 2005, it appointed a Patient and Public Engagement Lead, a Lorraine Denoris, but I do not know what became of her). It seems likely that the now-enlarged PCTs, whatever their merits, will have to delegate much to local sub-committees in order to be at all in touch with local issues.
The role and duties of the Chairman of a Locality Team need to be thought through and widely discussed to try and get a common approach. There is obviously a need to keep the job manageable. This means lots of delegation, not getting personally involved chairing sub-committees and special interest groups. It will require networking with voluntary groups and Social Services, as well as establishing good relationships with the Overview and Scrutiny Committees as well as the PCT Board and its locality sub-committees. On the last point, the DoH can re-organise the PCTs as often and how it likes: there is no obligation on PPI groups to follow these changes, and have their work organised by the DoH for them.

So here some ideas on a Job Description are offered below for consideration.

**JOB DESCRIPTION FOR TEAM CHAIRMEN**

1. Able to organise and hold meetings, getting the agenda and papers to members and local Trusts well in advance, giving team members and others invited to attend an opportunity to contribute to discussions, yet keeping to the time allotted to the meeting.

2. Considers that the team needs a local office in or adjacent to the PCT’s own, with some professional assistance in legal and procedural aspects.

3. Understands the need to get a wider patient and public involvement in healthcare than team members can provide on their own, and be prepared to work with others, such as BGOP (eg, 50+) and local healthcare charities, to that end.

4. Actively supports the case for all teams within the locality working together, not only those nominally associated with the one PCT.

5. Appreciates the need to get involved in the work of local sub-committees and Local Improvement Teams set up by the PCT and other local Trusts; and with the Overview & Scrutiny Committees set up by local government.

6. Believes that the Chairman should be ex officio Non-executive Member of the Trust Board, or at least have a speaking if non-voting rights at the Trust’s public meetings.

7. Considers that its reports should carefully considered by Overview & Scrutiny Committees, and if not, they should have the right to appeal directly to the Secretary of State.

8. Believes that the work of the team could be enhanced with regional and national representatives and executive, to relate with NHS Authorities and healthcare charities at the appropriate level.

**LINKS AND THE DEPARTMENT OF HEALTH**

**LINks—**

<table>
<thead>
<tr>
<th>as viewed from the top down</th>
<th>as viewed from the bottom up</th>
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<tbody>
<tr>
<td>Accountable to the Dept of Health</td>
<td>Accountable to Patients, Carers and the Public Volunteers (—although an honorarium might be considered for national and regional delegates)</td>
</tr>
<tr>
<td>Professional employees working together in:</td>
<td>and management committee members) and working together in:</td>
</tr>
<tr>
<td>A National and nine Regional organisations</td>
<td>Each With a Management Committee—</td>
</tr>
<tr>
<td>Chief Executive Officer</td>
<td>Chairman appointed by and from the other non-executive members</td>
</tr>
<tr>
<td>Other directors: Finance, Legal, The Knowledge/Communications/Events Appointed by the NHS Appointments Commission (Other staff appointed by CEO)</td>
<td>all appointed by Assembly (NB More non-execs than execs!)</td>
</tr>
<tr>
<td>National Assembly (1) 18 delegates (max 2/region), appointed by Regional Assemblies Regional Assemblies (9) Chairman appointed by and from 20 Delegates (max 2/forum), appointed by Health Economy teams LINk teams for each Health Economy Area—2007)</td>
<td></td>
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<tr>
<td>Chief Officer (125?) Appointed by the NHS Appointments Commission, (Other staff— Office manager and admin support— members appointed by CO)</td>
<td>Circa 20 members, appointed by local healthcare PPI voluntary groups Management Committee Circa 6 members. Chairman appointed from and by other members</td>
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SUMMARY

This memorandum describes the historical background to patient and public involvement in the British health system.

This is not a new phenomenon but extends back at least to the 19th century, in the form of voluntary sector governance of GP and hospital services, and in local government control of health care.

The growing role of the central state in health provision undermined existing broadly-based forms of patient and public involvement, which were finally ended with the coming of the NHS in 1948. However this was unopposed because the goals of a universal, comprehensive and free service satisfied users' major requirements of the health system.

Patient consumerism expressed through voluntary sector activity began to develop from the 1960s. A formal mechanism of patient and public involvement in the NHS was established in the 1970s with the Community Health Councils, which for the first time separated representative from managerial functions.

Consideration of these earlier forms suggests some inherent features, such as the tendency for power to remain with medical professionals and administrators rather than users, the scope for conflict between doctors and representatives of the public, the possibility that local choices may conflict with uniform national standards, and the tendency for voluntary representative bodies to attract those already active in public life.

History suggests that broad issues which policy-makers need to consider are: the specification of parameters for real local decision-making by patients and public; and the need to ensure consistently high levels of public awareness of representative structures in order to attract a wide range of participants.

Present proposals for strengthening local government’s consultative and community advocacy role could represent a return to the main direction of policy pursued prior to the NHS, of ensuring democratic responsiveness of health services through the local ballot box.

1. INTRODUCTION: AN HISTORICAL PERSPECTIVE ON PUBLIC AND PATIENT INVOLVEMENT (PPI)

1.1 The recent series of reforms which replaced Community Health Councils (CHCs) with new forms of PPI in the National Health Service (NHS) are apparently driven by two dominant political assumptions. These are:

(a) An understanding of the citizen as critical consumer, and no longer the deferential recipient of services.

(b) The premise that welfare states fall prey to producer interests and that these must be tempered by user input.

1.2 Although both these assumptions suggest that PPI in the health system is a new issue, it has an extensive history, stretching back long before the inception of the NHS in 1948. Earlier forms of PPI include:

(a) The oversight of general practitioners (GPs) by friendly societies before the introduction of National Health Insurance (NHI) in 1911.

(b) Public involvement in the governance of voluntary hospitals before these were nationalised under the NHS.

(c) The local democratic processes to which municipal health services were subject before 1948.

(d) The creation of CHCs as an aspect of the 1974 health service reorganisation.

1.3 This memorandum provides an historical perspective on the Committee's second and third terms of reference, consideration of the different forms of PPI and the background to the reform process. It will discuss in turn these earlier experiences, and show why PPI has been weak within the NHS.
2. **Before National Health Insurance: Public Oversight of GPs**

2.1 The central state’s involvement in primary care delivered by GPs dates back to 1911 and the coming of National Health Insurance. Prior to this sickness insurance was widely provided by non-profit, mutual organisations known as friendly societies.

(a) Benefits were a cash payment to replace lost income and GP attendance to certify and treat the sickness.

(b) Membership expanded from the 1850s. By 1911 probably some 40% of all adult males had sickness cover.

(c) Friendly societies had strictly observed electoral procedures through which working-class members could serve on management committees.

2.2 GPs were employed locally by friendly societies to provide services, usually on an annually renewable contract. The contractual basis of employment meant that management committees exercised direct leverage over the appointment, conduct and costs of GPs.

2.3 In the early 20th century friction between GPs and societies had developed. The bacteriological revolution raised the status of medicine and GPs resented being subject to committees of workers.

(a) The British Medical Association (BMA) instigated the “battle of the clubs”. It documented local disputes and drew up guidelines for members to follow in dealings with friendly societies.

(b) Conflict was mostly over the question of remuneration and lack of deference on the part of patients.

(c) But GPs also argued that independent medical judgement might be sacrificed if they were beholden for their livelihood to the whims of users, as expressed through management committees. Examples included over-prescribing of drugs, colluding with malingers and unnecessary home visits.

2.4 NHI substantially increased the numbers of citizens with sickness coverage. It also reconfigured the relationship between users and GPs in favour of the doctors.

(a) Friendly societies became agents of public policy as “approved societies” for the administration of NHI, but without their previous leverage over GPs.

(b) The annually renewable contract was replaced with a per capita fee for participating GPs serving a “panel” of patients.

(c) Panel GPs were now answerable to a local Insurance Committee, in which user representation was diluted.

2.5 Conclusions:

(a) A form of PPI in primary health care dates back at least to the 1850s.

(b) The “battle of the clubs” demonstrates that PPI can be a source of conflict between medical professionals and users.

(c) Behind this conflict there was a status asymmetry presumed by doctors between themselves and users, founded on social class and scientific expertise.

(d) The doctors’ dislike of PPI cannot be ascribed solely to self-interest. Concerns that independent medical judgement should not be compromised by lay people remain current today.

(e) User power was diminished as a result of state intervention, though coverage, quality of service and GP remuneration all improved.

3. **Before the NHS: Public Involvement in the Governance of Hospitals**

3.1 Prior to 1948 most acute hospital care was provided in the voluntary sector. The establishment of independent voluntary hospitals began around the 1750s and their main features were:

(a) Reliance on voluntary funding sources, originally philanthropy.

(b) Honorary and unpaid service by hospital consultants.

(c) Volunteer management by unelected lay trustees.

3.2 Voluntary hospital management committees were self-selecting bodies drawn from local industrial and professional elites and religious activists. Their powers included:

(a) Appointment of doctors, though this was ceded in the later 19th century to medical committees.

(b) Control of admissions, also increasingly ceded to doctors in the later 19th century.

(c) Management of income and expenditure.

(d) Regular visiting of the hospital and oversight of medical care on behalf of patients and donors.
3.3 After 1914 the composition of management committees became more representative of hospital users. This was because of the changing structure of hospital funding.

(a) From 1914 charity was superseded by user fees and payments from working-class hospital contributory schemes.

(b) Contributory schemes provided voluntary insurance against hospitalisation. For a small weekly sum, workers were exempt from means-tested user fees on admission.

(c) Contributory schemes had strictly observed workplace electoral procedures allowing ordinary subscribers to serve on hospital governing bodies.

(d) Trade unionists and friendly society leaders figured prominently amongst those who took such positions.

(e) Typically these “worker governors” were in a minority on hospital management committees, with a third of the seats.

3.4 Despite their minority position the worker governors exerted some leverage over hospital policy because contributory income was essential to finance. For example:

(a) They expressed patient concerns over issues such as waiting times, visiting rights, and medical treatment. This was a minor part of their work.

(b) They ensured that contribution rates were kept low relative to local wages.

(c) In some areas they rejected means-testing and kept the hospital free at the point of use.

3.5 Occasionally worker governors expressed strong preferences arising from the special interests of local contributors. This placed them in conflict with doctors and hospital authorities. For example:

(a) Gloucester 1920s: anti-vaccinationist governors wanted the voluntary rather than the isolation hospital to treat smallpox patients. They were overruled.

(b) Sunderland 1930s: worker governors wanted to sack hospital doctors taking industrial injury cases on behalf of coal-owners. They were overruled.

(c) Nationally: They supported trade union actions to improve pay and conditions of nurses and ancillary workers. Here their dual role as guardians of contributors’ funds meant disputes tended to be resolved consensually.

3.6 Conclusions

(a) A form of PPI in hospital governance dates back over two hundred years.

(b) Voluntary governing bodies were not directly representative of users. Initially they were dominated by wealthy philanthropists. When they became broader, working-class representation fell to those already active in the labour movement. This tendency for voluntary representative bodies to attract those active elsewhere in public life is likely to be repeated today.

(c) Worker-governors were most successful in defending user interests in respect of equitable funding and free access to services, both principles later enshrined in the NHS.

(d) Worker governors were least successful when they expressed local preferences at odds with medical or managerial opinion. Ultimately power remained with medical and professional elites. Localism had clear limits where it was at odds with national priorities and the same is likely to be true today.

4. BEFORE THE NHS: MUNICIPAL HEALTH SERVICES AND LOCAL DEMOCRACY

4.1 Prior to 1948 much public expenditure on health services was made through local government. It came principally from local taxation, although some services were part-funded by Treasury grants. The major municipal health services of the interwar period were:

(a) Isolation hospitals, mental hospitals, long-stay hospitals (originally the Poor Law workhouses) and by the 1930s some general acute hospitals.

(b) Environmental services including sanitation, housing and waterworks.

(c) Tuberculosis (TB) dispensaries and sanatoria.

(d) The school medical service.

(e) The maternity and child welfare (MCW) services, including midwives, clinics and hospitals.

4.2 These services were overseen by committees of county borough, county or district councils.

(a) Public health committees were made up of elected council members, with a permanent public official, the Medical Officer of Health, acting in an advisory capacity.

(b) Committee structures varied between councils. In large cities and counties health responsibilities were also exercised by education, mental health and public assistance (Poor Law) committees.

(c) Local health policy and expenditure levels were therefore subject to local democratic procedures and committee makeup largely determined by party composition.
4.3 There was considerable variation between local authorities with respect to levels of health spending and the comprehensiveness of services.

(a) Spatial variation is now criticised as a “postcode lottery”, but government in the 1930s regarded it as a desirable manifestation of local choice in action.

(b) It sought to aid disadvantaged areas by refining the central grant mechanism, so that greater Treasury support for health expenditure went to poorer authorities with greater need.

(c) None the less geographical unevenness remained on the eve of the NHS.

4.4 There is no clear research evidence that local choice expressed in the ballot box directly influenced local health policy.

(a) A key determinant was wealth: richer areas spent more on health, poorer areas spent less.

(b) There was a weak positive correlation between Labour representation on councils and greater expenditure on TB and MCW. However these services were those sustained by Treasury grants which privileged poorer areas likely to return Labour councillors. There may therefore be no causal link with party policy.

(c) Another measure of “progressive” health policy was the degree of improvement of Poor Law hospitals. Councils led by all political parties undertook this. Party programmes were not the key determinant.

4.5 Conclusions

(a) Another form of PPI with which Britain experimented before 1948 was the situating of health services within local government, thereby making them subject to local democracy.

(b) In practice local choice influenced committee make-up although more specific democratic influence on health policy is hard to detect. Health was only one among many issues on which voters made their choices at local elections.

(c) Localism was therefore determined largely by the resource base and by public officials.

(d) Localism led to uneven provision. It was, and perhaps still is, inherently at odds with the goal of universal high quality services.

5. THE COMING OF THE NHS: WHAT HAPPENED TO PPI?

5.1 The NHS Acts of 1946 and 1947 ended all these arrangements.

(a) The Insurance Committees overseeing GPs were replaced by Executive Councils with a similar lay/professional mix.

(b) Both voluntary and municipal hospitals were nationalised and placed under the control of Regional Hospital Boards (RHBs) and local Hospital Management Committees. Their members were appointed by the Minister of Health.

(c) Most personal health services were removed from local government, leaving only environmental health, domiciliary care, school medicine and some maternity care subject to local democracy.

5.2 There was no significant political opposition to these changes.

(a) The Labour Party had previously favoured a local government-run NHS, but this proved politically difficult due to the objections of the BMA. The nationalisation and regionalisation scheme was a pragmatic alternative.

(b) The contributory scheme movement accepted its demise, although existing worker-governors strenuously protested their exclusion from the new hospital management structures.

(c) Aneurin Bevan, architect of the NHS, assumed that democratic control of health services would be enhanced through ministerial oversight and parliamentary scrutiny. He had had first-hand experience in South Wales of earlier forms of PPI, through his positions in a local Medical Aid Society, and as a voluntary hospital governor. Bevan did not lament the loss of these structures.

5.3 In contrast to earlier arrangements there was no direct user representation on the RHBs.

(a) In practice RHBs were dominated by doctors, local politicians, academics and the professional and industrial elites previously active in voluntary hospital management.

(b) There was a preponderance of elderly males on these boards.

(c) There was no structural provision for the retention of existing worker governors.

(d) The new system of ministerial appointment led to the under-representation of the labour movement. Bevan’s reluctance to appoint trade unionists was probably a concession of to pacify opponents of the NHS.
5.4 The absence of PPI was not deemed problematic in the 1950s and 1960s, and it is only in the last 30 years that a new concept of "patient consumer" has emerged.

(a) Opinion poll evidence from the 1950s showed very high levels of public satisfaction with the NHS.
(b) Voluntary sector groups representing health care users were initially few in number and did not exert pressure on policy.
(c) Only with the arrival of the Patients Association (1963) can the first signs of the health consumerism of today be clearly identified.
(d) Patient groups linked to specific diseases or to public health issues began to proliferate in the 1970s and 1980s. Their emergence was an aspect of a broader consumer movement in industrialised societies, with a focus on consumer rights and standards of services.

5.5 Conclusions

(a) The advance of state agency in health provision terminated existing arrangements for PPI.
(b) This had no significant opposition because the goals of a universal, comprehensive and free service satisfied users' major requirements of the health system.
(c) The managerial structures bequeathed by Bevan privileged the interests of providers—doctors and administrators—over those of patients.
(d) Therefore the NHS was poorly equipped to accommodate the emergence of the patient consumer from the 1960s.


6.1 As yet there has been no detailed historical evaluation of the CHCs, although there has been limited contemporary policy research.

6.2 CHCs were established in the 1974 NHS reorganisation.

(a) This aimed to tackle the unsatisfactory "tripartite structure" of the NHS by creating new tiers of area and district health authorities. CHCs were created at the district level.
(b) They were not initially a policy response to the new consumerism in health but were proposed during the consultation process to compensate for further reduction in the role of local government.
(c) However in the parliamentary debates they were championed by consumer interests, which lobbied strongly for their autonomy.
(d) Government reluctantly conceded greater financial and political independence for the CHCs from area health authorities. Thus for the first time a representative mechanism was created which was separate from the health system's managerial structure.

6.3 The structures and functions of CHCs were as follows:

(a) They consisted of nominees of local government (1/2), voluntary organisations (1/3) and regional health authorities (1/6).
(b) This method produced a membership which was a "distorting mirror" of the population, being disproportionately middle-aged, male and middle class, and already active in other areas of public life.
(c) However, the voluntary sector membership brought in new people, particularly from health related associations, and later from new movements, such as women's and minority groups.
(d) The CHC’s role was to act as community watchdog (overseeing services and assessing local needs) and patients’ advocate (providing assistance and advising on complaints), and to participate in health planning (through consultation procedures).
(e) The detail of how CHCs would carry out these activities was largely unspecified and no criteria for assessing their effectiveness were developed. CHCs interpreted their roles in different ways, with some more passive than others.

6.4 CHCs subsequently had a long, but insecure existence and were abolished in 2003.

(a) The Thatcher government considered their abolition in 1982 during its purge of quangos, but pulled back fearing a defensive outcry.

(b) The coming of the internal market undermined their status, both because it provided a new mechanism for assessing patient demand, and because consumer protection was now directed to the individual not the community.

(c) There is some evidence that CHCs were easily disregarded. In 2002 the vast majority of CHC referrals to the Secretary of State were over cases of inadequate consultation with health authorities or trusts.

(d) Labour was a staunch defender of the CHCs in the 1990s. However once in power it proposed their abolition on the grounds that they were outdated, lacked teeth and suffered from low public awareness.

(e) One leading historical assessment of this volte-face claims that government sought to appease provider interests by removing an oppositional body and replacing it with the weaker Patient Advocacy and Liaison Service.74

7. GENERAL CONCLUSIONS

7.1 Historical perspectives on forms of PPI

— Although current debates about PPI are framed as a response to contemporary health consumerism, the involvement of patient and publics in the organisation of health services has a long history in Britain.

— Like today earlier forms of PPI sought to represent the interests of those who paid for and consumed health services, to those who provided them: doctors and administrators in the public or voluntary sector.

— Under these earlier forms of PPI power and authority in the British health system tended to remain with provider interests rather than users.

— At every stage the advancing role of the state reduced the power of PPI structures, although the achievement of universal access, comprehensive provision and equitable funding in 1948 meant that this was unchallenged.

7.2 Historical perspectives on the design of PPI

— Provider interests (eg “club” doctors, voluntary hospital administrators) have tended to be wary of PPI (friendly society committees, worker governors) as a potential source of opposition.

— However this may not simply be a case of professional or bureaucratic monopolisers protecting self-interest. Localism has in the past been inimical to medically optimal policies, to rational resource allocation and to uniform national standards. Policy makers need to specify clearly at the outset the scope for real local decision-making by PPI bodies.

— In the past, participants in voluntary forms of PPI have been self-selecting, likely to represent special interests or to be drawn from limited social constituencies defined by age, gender and social class. Given contemporary evidence for high levels of passive citizenship (poor local election turnout, low levels of voluntary association membership) the same is likely to be true today. Mechanisms are needed for ensuring consistently high levels of public awareness of PPI structures in order to attract a wide range of participants.

— The alternative approach was to use the ballot box, and there are some current indications that local government may again take a larger role. In addition to the establishment of local authority Overview and Scrutiny Committees there are moves towards greater joint working between the NHS and local government on health and social care. Present proposals for strengthening local government consultation and community advocacy75, could represent a return to the main thrust of policy before the NHS, of ensuring democratic responsiveness by situating health services within local government.

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Centre for History in Public Health
London School of Hygiene and Tropical Health
January 2007

Evidence submitted by Nick Green (PPI 77)

PATIENT SAFETY AND THE AUTONOMY OF LINKs


Independence

1. The autonomy of Patient Forums was embodied in the Statutory Instruments (National Health Service Reform and Health Care Professions Act 2002 Statutory Instrument 2003 No 2123 and 2124) but these were subverted by CPPIH.

2. No budgets have been allocated to any Patient Forum. A formal response from the Health Committee is required. CPPIH witheld the money needed to do the job. A sum of at least £70 million has been improperly accounted. CPPIH has thus disqualified itself from taking any part in determining the form of LINks and this must be investigated.

3. In many parts of the country, particularly London, Forum Support staff did not accept direction from members as explicitly required by Statutory Instruments. It is not the case that Data Protection legislation requires this as CPPIH claimed.

4. Contact details with other Forums were deliberately withheld (again in violation of Statutory Instruments). It is not the case that Data Protection legislation requires this as CPPIH claimed.

5. CPPIH were aware of its non-compliance with the law. This produced many complaints about members who had criticised CPPIH. Members had no remedy and many resigned. The complaints code of practice was often breached by CPPIH itself. The contractual arrangements with Support Organisations and past CPPIH accounts must be subject to full forensic scrutiny so the mistakes of the past cannot be repeated.

6. In view of paragraphs 1–5 a National Body elected from Forums and LINks should be created with independent support and legal staff. A budget of £60,000 per annum should be sufficient per existing Forum as it is merged into LINks under Local Authorities. An annual subscription should be paid to the National body.

7. The existing Statutory Instruments were adequate and simply require strengthening in view of the experience outlined above of many, if not most, Patient Forums in the country.

Remit

8. The random unannounced Inspection visits to NHS premises is the single most important function of Patient Forums. In view of the difficulty of NHS staff complying with hand washing and other patient risk minimisation procedures (eg cleaning, control of nosocomial infection, patient nutrition, accurate and timely delivery of appropriate treatment) inspection procedures should be developed further.

9. A model adapted from the Home Office funded Independent Custody Visiting Association, who visit custody suites in Police Stations to ensure proper treatment of detainees, could be applied.

10. No patient risk minimisation training was given by CPPIH and this gross deficiency should be corrected and enhanced for LINks with the right to inspect treatment records when Patient consent is given.

11. Training should be given to enable scrutiny of PCT expenditure and hospital accounts. This should be from the perspective of reducing preventable accidents and promoting error reduction in diagnosis and treatment.

12. Trusts should be able to give LINks members clear statistical evidence of beneficial outcomes for funded treatments.

13. This may be resisted because practitioners do not routinely acknowledge the general error rates in medical treatments.

14. 50% of Death Certificates are wrong (Sington and Cottrell). Staff reported 840 lethal accidents to the National Patient Safety Agency in its first report whereas Sir Brian Jarman at Imperial College estimated 40,000 lethal accidents.

15. The under reporting of accidents likely has its origins in unfair disciplinary procedures within the Healthcare professions that could also benefit from routine LINks scrutiny.

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76 On 24 July 2005 I received an unsatisfactory reply from my MP Glenda Jackson and wrote:

"It seems to me the Minister's response is wrong headed given the Statutory Instruments 2003 No 2124 (Functions) and 2003 No 2123 (Membership and Procedure) adopted by Parliament.

Is there someone on the Health Select Committee and/or the Public Accounts Committee that might be prepared to listen seriously to Forum members about the issue of accountability for money for Forums?"

I received no reply. From Treasury's "Productivity in the UK" Stationery Office Limited 11/00 19585 we can estimated waste in Public Expenditure at 52%. In this case the chain of irresponsibility is established.

77 Michael English, chair of the London Region Patient Forum Executive, will present the "Dirty Dossier" of Dr Janet Albu, chair of University College Hospital Patient Forum, as part of his submission to the committee. This documents the abuse of the complaints procedure by CPPIH to silence its critics.

78 http://jcp.bmj.com/cgi/content/full/55/7/499

79 http://www.ppif.org.uk/#in126
Membership and appointments

16. Existing arrangements from Statutory Instruments are satisfactory but potential conflict of interest by medical charity members and local authority Social Services must be open to full scrutiny.

Funding and support

17. Guaranteed funding at the rate of £50,000 per year per existing unmerged Forum with a subscription of £10,000 to a National LINks Body who will enforce standards of recruiting, reporting and training. LINks should report openly to anyone they wished and have full access to legal advice. Initiation of legal action against failing hospitals, contractors, practitioners etc should be considered. LINks Funding should be inflation index linked for next five years. Total costs are estimated at around £30 million per annum as with CPPIH. Support staff contracts should be subject to approval and monitoring by LINks.

Areas of focus

18. Patient safety concerns underlie every complaint that patients make. Authorities frequently deny this and the complainers are often labelled as malicious, litigious, neurotic and trouble-makers as the recent report by Action against Medical Accidents (AvMA) found.\textsuperscript{80}

19. Unnecessary delay is also a major concern of patients with chaotic use of existing facilities maintained to feed the private sector and the waning status of the experts involved. Delay circumvents intelligent questioning of agreements to treat by patients. The negative and positive predictive value of diagnostic tests, for example, is rarely made known to the patient. Recent work at Arrow Park A&E Department on the “lean” approach is very encouraging\textsuperscript{81}. Zero length queues without increased expenditure appears to be viable.

Statutory powers

20. Right to full inspection of all NHS premises and premises where NHS work is contracted must be re-enforced. Full access to all hospital records including financial, contractual and patient records where patient consent is given. The commercial confidence doctrine serves only to subvert Best Value and quality constraints.

Relations with local health Trusts

21. Regional Liaison Committees of LINks should be set up.

National coordination

22. A National Body to regulate and develop activities should be elected from LINks members with a Board of Trustees. The Health Committee may care to consult further on this question.

HOW SHOULD LINks RELATE TO AND AVOID OVERLAP WITH:

Local Authority structures including Overview and Scrutiny Committees

23. Local concerns should be reported to Overview and Scrutiny Committees but LINks should be free to report to whomever they wish. All reports should be in the public domain with anonymisation if appropriate and be accessible on a central website- avoiding the appalling “Knowledge Management System” model of CPPIH whose user interface was so bad special training was required. A Wikipedia approach should be adopted.

Foundation Trust boards and Members Councils

24. LINks membership of boards and councils should be considered but the essential independence of LINks must not be compromised.

Inspectorates including the Healthcare Commission

25. The Inspectorates and Commission could develop inspection procedures for LINks with eventual ratification by the LINks National Board.

\textsuperscript{80} http://www.avma.org.uk/

\textsuperscript{81} “Redesigning the broken processes in the Health Service” http://www.cppf.org.uk/#in244
Formal and informal complaints procedures

26. Procedures should be monitored by LINks.

In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

27. As per legislation but LINks should insist on clear presentation of performance indicators to justify any intended reorganisation.

About Me

28. I am Chairman of the Real Time Study Group, an academic and industry software design group set up in 1997 to examine the “Better Government” proposals.

29. As a past member of Camden and Islington Mental Health Trust Patient and Public Involvement Forum I produced the Patient Public Involvement Organisation website in 2003. We focus on reducing error and delay in the NHS http://www.ppif.org.uk. We are informally governed by a Discussion Forum of some 52 self appointed patient and public users and take contributions from both Forum members and ex-Forum members from around the country. We publish Patient Safety oriented expert opinion from professional, academic and government sources. We summarise local newspaper reports of local Patient Forum activities. From our inception we have advocated a National Patient Forum Organisation.

Nick Green
Patient and Public Involvement Forum Organisation
4 January 2007

Evidence submitted by James Halsey (PPI 20)

1. I have been involved as a lay person in the NHS for many years in a number of different areas, namely:
   — I work as a volunteer in A&E.
   — I have sat on a number of committees in my local acute hospital trust.
   — I am attached to the Patient and Carer Network at the Royal College of Physicians (London).
   — I have sat on 63 Independent Review Panels (under the previous NHS complaints process).
   — I accepted an appointment as an associate with the Healthcare Commission with a view to becoming involved in the new complaints process.

2. I was proud and felt privileged to be involved with the previous complaints process which I knew to be truly independent and free from interference from any quarter and hoped that the new complaints process under the Healthcare Commission would be likewise.

3. I believe that there have been very few independent review panels held since the Healthcare Commission took responsibility for complaints and that finance may be one of the major considerations when deciding whether or not to hold an Independent Review Panel.

4. In my view the new complaints process is not patient-focused and the correspondence from the Healthcare Commission to complainants is not personalised in any way and because I feel so strongly about the independence of any NHS complaints process have declined to be involved in the new complaints process, a decision that has given me real concern.

5. As far as I am aware there has not been any public satisfaction survey regarding the new complaints process but as you are aware the strength of any survey depends on the questions.

6. I was also appointed to the Patient and Public Involvement Forum at my local acute hospitals trust but resigned after six months as I felt the implementation process was rushed and the Forums were poorly trained, resourced and supported and despite having statutory powers to monitor and inspect healthcare services, lay people are not equipped to do so and need clinical advice and support to be effective.

7. The majority of the public are unaware of the existence and function of PPI Forums, the majority of which have had little impact and have been ineffective. Their function also depends upon the genuine cooperation of the Trust.
8. I am passionate about patient and public involvement in the NHS but unfortunately my experience is that in the majority of cases it is a tick-box exercise. The only exception is my involvement with the Patient and Carer Network at the Royal College of Physicians (London). Members are involved in all College activities where they have an equal voice as College members and their input is encouraged, welcomed and valued. I think the Patient and Carer network is a model of genuine Patient and Public Involvement in the NHS and you might like to consider contacting the Patient Involvement Unit at the College for more details.

What is the purpose of Patient and Public involvement?

9. To bring the voice of an informed public to those making decisions on the provision of healthcare with the aim of improving standards of healthcare and ensuring its availability as and when needed. To make robust efforts to try and ensure that it is a National Health Service and not a “Postcode Health Service.”

What form of Patient and Public involvement is desirable, practical and offers good value for money?

10.  
   — Volunteering (for reasons below).
   — Choose to be involved.
   — Not subject to any government targets, entirely patient and staff focused.
   — Free from interference from any quarter.
   — Criminal Records Bureau (CRB) checked.
   — No cost involved apart from identifiable clothing.
   — Know staff, geography and structure of NHS site.
   — Can carry out in patient surveys for PALS officers and any other approved Agency.
   — Eyes and ears of the public.
   — Can address concerns before they become complaints.
   — The Institute of Volunteering Research is undertaking a project to gauge the impact of Volunteering in the NHS.

Why are existing systems for patient and public involvement being reformed after three years?

11. The implementation process for PPI Forums was rushed and the Forums were poorly trained, support and equipped. Even though they had statutory powers to monitor and inspect Healthcare Services they were not equipped to do so, needing clinical support and advice to be effective. The majority of the public had no idea of the existence of PPI Forums and their function and the majority have had little impact and have been ineffective.

How should LINKS be designed?

12. Look at the failings and shortcomings of the PPI Forums, take stock, learn lessons and ensure that the same mistakes do not happen again.

In what circumstances should wider public consultation (including under Section 11 Health and Social Care Act 2001) be carried out and what form should this take?

13. There seems little point on many occasions of conducting a public consultation process when Government has already decided to implement major and minor changes to the NHS. The latest example of yet more changes goes under the title “reconfiguration”, many facets of which have already been implemented despite public opposition. I would ask you consider obtaining evidence-based data which confirms that public opinion has changed Government thinking. Sir Ian Carruthers has been appointed to carry out a six month review of all plans around the country to cut services and close Units to see if more can be done to win public support for change which in my view will take place, despite public opposition.

I am willing to appear before the Health Committee if required.

James Halsey
3 January 2007
Evidence submitted by Mr U Hawtin (PPI 57)

1. The Purpose

If the national Health Service is to provide a credible and acceptable service then there needs to be a SYSTEM providing for a means of two way communication which is capable of providing a credible procedure and understanding, two ways, between the providers and the patients. Not only to inform as to the needs and desires; opportunity to submit, comment and criticise but also to convey compliments and gratitude.

2. The Form

The system needs to provide for auditing to ensure it works, to ensure credibility and that notice is taken of it. It must provide for cross representation of the public, independence of Dept. of Health and other governing bodies, both Central, National and local government. There must be partnership, close working and a good relationship and just going through the motions or establishing a peasant and lord of the manor approach is not acceptable.

2(a) In my opinion and experience, the elimination of Community Health Councils was a mistake and has been shown to be based on political party and Government desires to reduce the involvement of patient and publics, except when an election is in the offing. It has been demonstrated that none of the replacements have shown to be an advancement in the 3 issue. Not only in the membership then represented but in the Council employing appropriate staff to perform the functions that they decide they are capable of. Not necessarily a Commission employing a middle man organisation of persons appointed by any other Commission. (Appointments) Certainly the majority need to be established from those citizens who already have or are willing to experience working for or in voluntary and charitable institutions with experience of health systems even in a lay capacity. Many of whom have experienced the problems and traumas of involvement in health systems.

2(b) If it is to be that most of them if not all will be expected to participate as unpaid volunteers, apart perhaps from the Chairman then this organisation should be empowered to avail themselves of professional administration and organisational staff and deal with their own budget, as well as being empowered to co-opt members (As full members or just for a particular exercise). There exist only too many departments and bodies who are willing and able to give advice and some form of supervision in regard to efficiency and financial matters. It surely is a system that provides value for money.

3. Existing Reform

The present course of reformation is just a continuation of the disease that seems to have affected the Health Service for many years. The perception is that either those in authority do not know the answers or are prevented by party dogma from taking the steps that have been identified as being needed and are expressed at the moment as a close working relationship, partnership working, transparency etc etc, but which the authority is not willing to take.

4. LINks

Again it is noticeable that someone seems to think that the answer is provided by a reorganisation. Another disease that the Health Service suffers from; devise a new gimmick or a new buzz word. Why is not possible to retain a title that everyone is just getting to know and recognise? Is it done in order to provide a placebo for local government bodies and to keep the political party structure in place.

4(a) The next six bullet points, from the press release, simply repeat the philosophy that seems to have been established over the rules by the academics and administrators. Establish rules, constitutions, then the administrators and the supervisors are not required to operate whatever personal skills they have but can quote the rules, which are so often restrictive, so as to remove from them any danger that their ideas may not be acceptable to their political bosses. This should be simple and not complicated but should be devised in such a manner as to allow the organisation room to breathe, to evolve and change in such a manner that new legislation is not always necessary That would often avoid the debates that occur between political parties and members usually to the detriment of the voters.

5. National Coordination

I am not sure that national co-ordination, whatever that means, is necessary apart from perhaps a circulation of good and identified practice and providing a convenient system for the administrators. Cannot the Resource Centre provide that. Experience certainly seems to show that problems that concern the patients and the public are local. Are not the needs local, the patients and the public live in localities it is only the need for specialist skills which are best served by specialist centres.

Mr Hawtin

January 2007
Evidence submitted by Dr John Hyslop (PPI 11)

Patient Centred Feedback, A Voice for Each Patient

1. To be effective quality management/clinical governance needs be aligned with the clinical management paradigm but also with the patient. Quality cannot improve without feedback. Patients and peers should be able to inform clinical team leaders of good and bad services.

2. The current feedback/survey tools are non-specific, post-dated, selective and drip down, rather than directed to the point of managing service change, the clinical team leader.

3. The proposal is anonymous electronic patient feedback via domain portals associated with the Electronic Health Record. The feedback is specific to that episode of team service, being identified through Healthspace or Choose and Book.

4. Feedback is a tool to place quality central to service delivery imbedded where the commissioners' money goes. The final common denominator closest to patient care delivery is the clinical team and therefore the emphasis in delivering all feedback and the quality agenda should be at this dynamic level.

5. As a benchmarking exercise the patient perspective can also inform fellow patients, commissioners, and the Healthcare Commission.

6. Patient complaints generate a lot of work and consume enormous management and clinical time. This could be improved by some integration with patient feedback.

7. Human interaction and resolution is led through dialogue. Feedback formally creates that dialogue where it might not exist. It is “offer and response” as in any negotiation and as such engages the patient, the individual, with the service. That engagement at clinical team level will influence the good to do better and the bad to change their game, not least because the dialogue is on the record and cannot be ignored. Feedback, therefore, is a persuasive tool that permeates all aspects of service delivery not just as a point of reference but also as a flag of quality of care.

8. The relationship created is constructive, gives voice and responsibility to, whilst engaging with, the patient.

9. There are thus benefits for the patient, the service, each team and subsequent patients.

10. The patient benefits:
   - Gives each patient a voice, guaranteed to be heard.
   - Other patients can review service choices alongside a feedback graphic.
   - PALS are supported.
   - Engages the individual patient.
   - Good and poor services can be commented on.
   - Individual views can be raised in an anonymous format without stigmatisation.
   - Patients would know that their feedback is on the record to influence service development.
   - They can become engaged in an active dialogue to resolve issues.
   - Values the patient’s perspective.
   - Enhances the patient role beyond representative “expert patients”.

11. The service gains:
   - A tool to integrate quality, clinical governance and management into clinical team service delivery.
   - A Feedback summary, informs PAL’s, team leaders, institutions, the commissioners and the Healthcare Commission.
   - The feedback and actions arising are on the record.
   - Feedback on services can be audited.
   - Clinical governance is integrated with robust evidence at each team level.
   - The role of patient advocates and PALS is supported.
   - Discreet and separate from but informs critical incident reports and complaints.
   - Good and poor services will be highlighted leading to best management through clinical governance.
   - Issues that might generate complaints could be actively managed with a timeline of evidence and process.
   - Norms of service will be determined (benchmarking).
   - Clinical team leaders’ actions and response to feedback will be on the record.
   - Professionals will spend time on feedback, practice reflection and audit of practice.
   - Institutions will have a record of quality, of a benchmarking of services teams and professionals.
— Teams will know what patients think of their service.
— Feedback can generate an active engaged dialogue to resolve issues.
— Creates a non-adversarial routine patient-centred quality initiative to influence service quality, delivery, professional practice and healthcare commissioning.
— Foundations of an evidence-based constructive complaints system and process.

12. The professional gains:
— Professional feedback can be noted within the appraisal folder informing revalidation.
— Complaints should have a feedback record/timeline for reference.
— Past feedback can support responses to complaints.
— Professionals will spend time on feedback, practice reflection and audit of practice.
— Professionals can contribute to resolve issues and influence local services to improve.
— Feedback files are “associated” with the professional, the team and the institution.

13. The clinical team leader benefits by:
— Allows quality to drive the change agenda.
— On the record feedback of good and poor delivery.
— On the record service change response to feedback.
— Helps guide team meetings and service change planning.
— Enables immediate response to issues or poor service.
— Feedback and responses/changes are on the record with clear justification.
— Teams will know how their service and professionals are perceived.

14. The current mish-mash of delivery of quality and clinical governance reflect its non-core position and lack of integration. The positioning of patient feedback as an anonymous tool at the level of the clinical team leader will integrate clinical governance into commissioning and delivery.

15. How to take this forward? Briefing papers confirm it’s within the art of the possible from choose and book episode or healthspace. The concept of patient feedback enjoys support of the Healthcare Commission, Harry Cayton, Marlene Winfield, (Head of Public Engagement Connecting for Health), Richard Jeavons, Monica Clark,(Patient Experience Team), Dame Eve Buckland, and with passing interest by Sir Michael Rawlins and Professor Paul Corrigan. But it is not policy, or funded yet. It is likely to be cheaper and more direct/timely, thus responsive, than current postal patient “surveys”.

16. There are external models of patient feedback but these are not ubiquitous, contemporaneous, routine, care episode identified and directed to the relevant clinical team leader. A Healthspace feedback domain can be all these things.

Dr John Hyslop
Consultant Radiologist, Royal Cornwall Hospital NHS Trust
21 December 2006

Evidence submitted by Robert Jones (PPI 18)

1. What is the purpose of patient and public involvement?

To involve the public in an understanding of the way in which services work in society and to contribute to refining them; to bring public concerns, ambitions and ideas to the attention of those who run the services and to have a realistic chance of influencing them.

2. What form of patient and public involvement is desirable, practical and offers good value for money?

Perhaps the best model might be derived from looking at what government has done since 2003, and avoiding the mistakes it made. This is more than a satirical point: the creation of the CPPIH and numerous forums was a bureaucratic nightmare and nonsense. Government had so little confidence in the ability of those it recruited to the Forums that it policed them with one of the most pettifogging and unpopular quangos that I have ever known. It sacked the dedicated, professional staff to which CHCs had enjoyed access, and replaced them with bidders from the voluntary sector—a system which worked well in some areas, disastrously in others, owing to the widespread differences in the quality of voluntary sector staff and the professional standards available there.
A new system should:

(i) have professional staff to work with the new bodies which will be created;

(ii) have dedicated office space;

(iii) have the ability to follow through projects and, ideally, complaints—or at the very least to receive anonymised data from complaints procedures; and

(iv) have statutory powers that are adequate but not excessively bureaucratic.

As to whether this will mean “good value for money”, there is no point in having a system of patient and public involvement if these conditions do not obtain. If the government is serious about it, therefore, the above are the minimum standards to which its new system should adhere.

3. Why are existing systems for patient and public involvement being reformed after only three years?

Because the system brought in under the legislation creating forums and CPPIH was inadequate and misconceived, arising as it did from the decision to scrap CHCs without due thought or, crucially, consultation about what would replace them. The argument put forward by ministers that the system is changing because the NHS has changed cuts no ice with forum members, and lacks all credibility.

4. How should LINks be designed, etc?

(i) Remit and level of independence: If the LINks are introduced, they should aim to maintain the “critical friend” approach towards the NHS that has worked reasonably well. They should be separate from the NHS, and the Local authorities in whose areas they work. They should have a scrutinising role, and they should seek to involve user groups and individuals, as well as marginalised elements in society. There needs to be a sense of realism however about their capacity to achieve the latter: “hard to reach” groups may be hard to reach because they do not want to be reached. It will take more time than volunteers are likely to have to corral the unwilling into participating in health decision-making.

(ii) Membership and appointments: There needs to be a core board, if LINks are to be open organisations, or scarcely organisations at all, involving a wide range of bodies and people. Appointments to that board should preferably be made by elected councillors or at least at as local a level as possible.

(iii) Funding must be adequate for the purpose; must be ring-fenced; and support should be given by professional, competent managers recruited and trained for the purpose. The voluntary sector does not have sufficient professionally competent people within it to provide the level of service required. Members of Forums are unlikely to tolerate a repeat of the organised chaos that has bedevilled their work over the last three years, and yet the new system requires the expertise they have acquired.

(iv) Areas of focus: These will vary locally and regionally, but if the LINks are to be based on local authority areas, ie, principal authority areas, they should relate to and with the NHS, social services and housing services and organisations in their LA area. They should also be encouraged to relate with LINks outside of their areas, to share experiences and concerns.

(v) Statutory Powers: At least a group within the LINks should have the statutory powers to visit NHS institutions and premises supplying NHS services. Local authorities, Trust Boards, and Foundation Trusts should be obliged to consult with LINks and to include them on key decision-making bodies.

(vi) Relations with local Health Trusts: LINks should expect to be consulted as of right in the work of the local Trusts and to have representation on Trust Boards and main committees. Trusts should be made aware that “consultation” requires more than having a representative on a board, however, to nod through change or add credibility to its decisions.

(vii) There should be a national organisation to which LINks affiliate, and this needs to be adequately funded. What it does not need to be is a controlling mechanism for the LINks, or—in short—similar to the CPPIH. It should act as a clearing house for ideas and a forum for discussion, and might be constructed along similar lines to ACHCEW, or the National Housing Federation. It will need to be controlled by its members so that it does not run the risk of following the example of the latter and gradually acquiring more powers and roles for itself.
5. How should LINks relate to and avoid overlap with

   (i) LA structures including Overview and Scrutiny Committees: There is no evidence that the Forums have fallen into the overlapping trap, and no reason why the LINks should do so. An informal relationship should be established between LINks and OSCs, so that representation may be locally agreed; but it should be mandatory for the OSC to appoint/accept LINks representatives, and probably vice versa.

   (ii) Foundation Trust Boards and Members' Councils: A formal relationship should be established at the appropriate local level; this should not be rigidly prescribed, but there must be an understanding that representation is mandatory. Again, overlap is unlikely to be a problem given there is sufficient legislative framework to establish the responsibilities of the LINK.

   (iii) Inspectorates including the Healthcare Commission: Overlap is hardly likely to be a problem here; as to relationships, the Healthcare Commission has an impressive record of involving Forums in its activities, and most Forum members are very happy to work with it. We will hope that its work and approach continues, and that through negotiation and trial, a relationship will be formed with LINks that will mirror the successful one that has been formed with Forums.

   (iv) Formal and informal complaints procedures: Since in my experience ICAS and PALS have been wholly ineffective, and are extremely bad at conveying useful information to Forums, it would be my hope that they should be abolished. I realise the government has already indicated that they will continue. I can only say that I regret this, and believe that the CHC role of investigating and seeing complaints through, complementing internal NHS systems and occasionally challenging them, was the right way, and I deplore the retreat from it. I believe that relations between LINks and the complaints systems are going to be extremely poor when members of LINks realise how frail the system of complaints has become and that the government will face further challenges on this front in the course of time.

   (v) In what circumstances should wider public consultation (including Section 11 of the H&SC Act 2001) be carried out, and what form should this take? If the LINks are to have anything like the scope envisaged for them, they could be the main consultee body. Given that the majority of people will never be interested or able to be involved in them, however, the system which presently exists to enable consultation ought to be maintained, provided that it is extended to cover nationally determined changes in service provision as well as more local decisions.

Robert Jones [comments are made as as individual]
Vice Chairman, Isle of Wight PPI Forum
3 January 2007

Evidence submitted by John Kapp (PPI 31)

What is the purpose of PPI?

1. To solicit the help of patients in the creation of a “patient-led” NHS, to make it similar to every other service industry.

What form of PPI is desirable, practical and offers good value for money?

The main legislative change needed is to give PPI representatives more power. They need statutory rights to sit on, speak and vote on all NHS committees concerned with patient care including the think tanks of the CEOs. Managers could find them valuable allies in their battles with doctors.

From their committee positions, patients have a disproportionate effect whether the say anything or not. The mere presence of a patient is a reminder of who the committee is there to serve. They could also participate in true “consultation”, as nothing can be hidden from them. At times they have to be a crumb in the bed or even a thorn in the flesh drawing attention to doctors’ arrogant attitudes.

Patient representatives need support in what is a tough job. On each committee there should always be establishment for at least two patient representatives, so that they can support each other. If for any reason a PPI rep cannot be present at any meeting, he should have power to appoint a deputy or a substitute so that there is never a vacant chair. They also need good secretarial service, as presently provided by CPPIH and the Forum Support Organisations.

PPI representatives need to be able to stand their own corner in meetings where they are not welcome. The more that they can be trained in the issues mentioned above, the better they will be prepared for the antagonism that is bound to occur at their presence.
Why are existing systems for PPI being reformed after only three years?

In my experience, those leading CPPIH and the PPI Forum support organisations did not understand what their objective was, or where they were going. They therefore could not unite their members into a team. People went off in all directions, with little to show for their efforts, resulting in frustration and many resignations and high turnover. If the issues discussed above concerning a patient-led NHS were accepted, a clear direction would be pointed, and better leadership would emerge.

How should LINKs be designed including

Remit and level of independence

LINKs remit should be to create a patient-led NHS by recruiting patients to sit with speaking, and voting rights on every committee concerned with patient care. They should be independently funded as was CPPIH so that they cannot become the poodle of any organisation. (eg local authority).

Membership and Appointments

It should be easier and quicker to become a LINKs representative than it was to become a PPI forum member. There is no need for every representative to have the police check.

Funding and support

As CPPIH.

Creating a patient-led NHS.

Statutory powers

To sit on every committee concerned with patient care with speaking and voting rights.

Relations with local health trusts

There should be a general recognition of the problems of patients playing doctors referred to in Q1A above, which otherwise will merely cause conflict.

National co-ordination

As CPPIH was doing.

How should LINKs relate to and avoid overlap with:

(a) Local Authority structures including Overview and Scrutiny committees.
(b) Foundation Trust boards and Members Councils.
(c) Inspectorates including the Healthcare Commission.
(d) Formal and Informal complaints procedures.

Patient representatives should make clear that they are representing the patient’s interest only. It should be written into their terms of reference that they should always speak from their own experience, and not be mandated to plug any party line.

In what circumstances should wider consultation be carried out and what form should it take?

No comment.

John Kapp

7 January 2007
Evidence submitted by Mandy Lawrence (PPI 26)

As a member of a MH PPI forum I have many concerns in the way they run and are organised.

In the last few months two people died (one person jumped off a car park, the other transferred from a psychiatric unit to a general hospital where they died). Not only have the Trust been very secretive about disclosing information but the PPI members have done little to support my concerns that there were potential issues regarding care provision and appropriate safety support for these two individuals.

I feel that PPI forums are often dictated to by the Trusts and members are muffled or pressure is put on for them to tow Trust party lines.

Trust members are in constant attendance at PPI meetings which does not allow PPI members to discuss issues, as a forum, independently. This sways the power balance very much towards the Trust who use bureaucracy and red tape to block questions and concerns.

The Chairman of the PPIF resigned and the Vice Chair took up a full time position and stood down from their duties, which means that the small membership who attend (four or five of us) have now to share Chairperson responsibilities with no training. We asked if this training could be provided and were told that no money was available. I find this appalling in light of the fact that funding to attend PPIF conferences and events, often miles outside of the county, are funded costing a lot more than local and essential training would.

I think there is a specific issue for people with mental health problems when trying to be involved in patient and public arenas. There is little understanding of or appropriate support and the care and well being of people with mental illness comes a very poor last to maintaining systems and bureaucracies that do nothing to help people to be involved fairly and effectively.

I just hope that the Link Networks are more democratic and empathetic, less bureaucratic and very much independent of service providers or other care organisations.

I also think any patient and public arena must acknowledge that people with mental illness tend to be on very low incomes and having to pay up front and claim back for expenses such as travel can often leave them with more financial difficulties.

Mandy Lawrence
PPI Forum Member
5 January 2007

Evidence submitted by Jean Lewis (PPI 23)

What is the purpose of patient and public involvement?

1. By and large service users, as taxpayers have a right and a civic responsibility to be actively involved in the NHS though it should be noted that they have little interest in the shaping of health policy, delivery and audit unless they have been adversely affected by service provision.

2. The government sponsored ideology of patient and public involvement in health has yet to cross the chasm which exists between long established medical paternalism and the mythical future of a “Patient Led NHS”. In this new world NHS professionals will truly value the involvement of patients and the public and use them at all levels of decision making not simply to endorse previously agreed decisions as happened in the recent consultation process preceding the reconfiguration of PCTs.

What form of PPI is desirable, practical and offers good value for money?

3. Some impressive evidence exists concerning the work of PPI groups. This can be found in the Patient and Public Involvement Forum’s Annual Report 2005–06 National Summary (www.cppih.org ) However what is not in evidence is the extent to which value for money audit of patient led innovations will be undertaken. Academic research studies into existing PPI achievements are urgently required to contribute to the question of the purpose of PPI.

4. The Annual Accounts for the Commission for Patient and Public Involvement in Health can be found in the CPPHI Annual Review The Facts and Figures 2005–06 and shows that £31.314 million was spent on supporting PPI activity. To understand the purpose of PPI it is not enough to show how much has been spent in supporting it but what has been the health gains for the public arising from this very substantial expenditure.
Membership and appointments

5. A major problem arises when attempting to define a service user. Every member of the public is likely to be a user of the NHS or is likely to become a user in the future. Therefore which members of the public and which patients should be asked to represent the views and opinions of all other service users? Should we settle for those members of the public who nominate themselves? Reasons for self nomination arise from self aggrandisement, boredom, failure in other walks of life eg relationships or career, to those who wish to defame the NHS because of a perceived failure of service delivery and of course there are those with deep conviction and a real will to shape health and social care. A careful selection process is essential, undertaken by experienced and consistent teams of accountable individuals using a process which demonstrates local democracy. Appointed LINKs members should understand and agree to public accountability. The purpose of PPI in the future LINKs organisation should be critically analysed and made explicit before attempting to recruit members of the public who not not fully understand the purpose.

6. The issue of democratic deficit is evident at NHS Board membership level where NHS Board members are unaccountable to their local communities. At the very least effective LINKs could ensure that Boards become accountable to the public via Annual Reports etc.

7. Direct democratic control can be seen to work in other public services such as Local Authorities, since service users and members of the public can remove those in authority if they are not satisfied with service provision. Within the context of LINKs it is vital that the fundamental differences in democratic control between Local Authorities and NHS Trust Boards is properly recognised. Service users who become members of LINKs will need to be politically aware of the fundamental democratic differences between the NHS and Local Authorities.

8. Without careful selection by an independent body then a dictatorship of the uninformed may project themselves forward as LINKs members, thereby undermining the purpose of patient and public involvement.

9. The purpose of a new type of patient and public involvement in the NHS should be defined by close scrutiny of the existing statutory form of PPI. Strengths and weaknesses should be distilled to ensure that future health and social care services are not influenced by vociferous minorities with single policy issues. To date a satisfactory formula has failed to materialise to ensure the right kind of balanced, participatory PPI democracy.

10. Any future PPI system should take note of the extent to which committed and caring members of the public are left feeling undervalued by the PPI process. Professionals are well rewarded for their attendance at meetings etc whilst PPI members are asked to attend for nothing (except for travel costs etc). Please note the discrepancies existing when lay assessors participate in the Quality Outcomes Framework system (QOF). GPs who participate in the QOF process are very well rewarded for their time whilst financial reward for lay assessors is sporadic across the country, varying by PCT.

11. At professional meetings PPI reps are usually out numbered by professionals who often use secret/exclusive, professional jargon to effectively exclude PPI members. Professional who attend meetings are often intent upon driving home vested interests for there particular department and have no time to spend on lengthy periods of consultation with members of the public who do not consider as equals.

12. The future effectiveness of PPI will depend upon a willingness by NHS professionals to attend education and training events to familiarise themselves with the purpose of PPI. They should not seek merely to legitimise their plans by demonstrating that they have consulted with patient groups.

13. Before actively recruiting to a future PPI structure, research is urgently required to identify the many and varied forms of PPI that already exist since there is a real danger of reaching saturation point where so many diverse groups are asked for their opinion. Very little consensus is achievable when disparate groups are asked for their opinion. The gain for the NHS is that the process demonstrates that the public has been consulted though the variety of responses means that little notice needs to be taken.

14. A new, statutory form of PPI should be clearly rebranded as something which is radically different to the small, often press-ganged, GP adoring groups set up to act as the PPI voice for GP’s thereby enabling them to achieve more points in their annual QOF process.

15. Future PPI members must feel more valued than in the present system. To become more valued they should be more carefully selected, with more public accountability. PPI should be in evidence in all key decision making activities in the new NHS. In particular GP’s should be actively involved in defining PPI member attributes. When GPs’ collectively reach a point where they say they are comfortable with PPI then LINKs will have succeeded where PPI is deemed to have failed.

National Coordination

16. With the impending demise of CPPIH who will represent LINKs members at national level? Who will provide training and set up opportunities for national networking events? Who will fund these activities?

Jean Lewis
Nottinghamshire County Teaching PCT PPI Forum (comments are made as an individual)

23 November 2006
Evidence submitted by Brenda O’Neill (PPI 143)

1. **What is the purpose of patient and public involvement?**

   1.1 To ensure that patients receive the highest quality/standard of timely care in the most appropriate setting as possible. To do this the care planners, commissioners, providers need information/evidence. Part of this is medical/clinical, scientific, best practice etc but a big part will come from patients (of their experiences) or potential patients (of their perceived needs).

2. **What form of patient and public involvement is desirable, practical and offers good value for money?**

   2.1 It needs to be sufficiently flexible, to meet the needs of local people, individuals and communities. And consistent, standard enough to make sense of the outcomes, evidence, opinions, ie interpret evidence to make (national) decisions.

   2.2 Any new PPI arrangement must get away from the committee style/structure. This disempowers some individuals who cannot relate to such structures—finding them restrictive and limiting.

   2.3 Boundaries—these also are limiting and do not necessarily reflect, for the want of a better description, the patient pathway. They are potentially practical and desirable but inflexible.

   2.4 Need to consider if the PPI arrangement is meant to be representative or empowering.

   2.5 I would take issue with less emphasis on those who have a voice—or those who already express their views. They are still needed and not everyone wants to express a view—which seems to be a huge assumption being made by Government and the Department of Health. Many people only want to express their view when it is relevant to them or their nearest and dearest—family or friends.

   2.6 NB—PPI is a communication tool that allows patients, the public, citizens, communities to inform provide feedback, input, comment in a timely fashion (throughout the planning cycle for example) and the NHS and Social Care providers/planners to seek views, respond, react, account for, plan, purchase and deliver the care.

3. **Why are existing systems for patient and public involvement being reformed after only three years?**

   3.1 For practical reasons in my view:

   — CPPIH is to be abolished, Impact of NHS reorganisations, and a PPI Forum relating to a specific NHS body does not relate to patients or the public.

   _Brenda O’Neill_
   
   _January 2007_

Evidence submitted by Jean Nunn-Price (PPI 139)

I joined the SW Oxfordshire PPI PCT Forum in December 2003 and subsequently was elected Chair of the Forum prior to its being subsumed in Oxfordshire PCT PPI Forum in October 2006. My experience includes working voluntarily both with PPI Forum colleagues and with the PCT Board, and conducting surveys of public, patients and voluntary organisations locally to draw out their concerns and represent them to the PCT.

I attended the SHA Conference on Tuesday 9 January and I broadly agree with their evidence to the Committee. The evidence that follows draws upon the SHA evidence to which I and colleagues contributed. I would be happy to give oral evidence if required.

*What is the purpose of patient and public involvement?*

Health Services that involve patients and the public in planning future provision and that welcome and respond to feedback on current provision, are more likely to get it right. I believe democratic accountability is important, and so is real empowerment of the community in challenging the organisation providing health services, whether government owned, a voluntary organisation, or a co-operative and mutual enterprise. The commissioner and provider of health services need to know that they will be challenged effectively by the public who are on the receiving end. It is now accepted that people need to be positively and actively involved with their own health and this means there should be opportunities for both collective and individual involvement.
What form of patient and public involvement is desirable, practical and offers good value for money?

Much more effective publicity needs to be given to the PPI role, so that everyone, including disadvantaged sections of the community, can participate. PPI volunteers must be properly resourced to relate to people with sensory or language difficulties, people with dementia and those confined to their home or to an institution. I welcome the proposal that the new LINks will work with voluntary organisations, as they are more likely to have developed the right contacts and techniques for two-way communications with the hard-to-reach sections of the community. But no one voluntary organisation should be given the power to manage a LINk, as they have their own vested interests and cannot be seen as independent.

It would be helpful if the Government could clearly define what it wants the system of PPI to deliver. Without this there is no means to judge if the system has succeeded or failed. Once established, if there could be a planned independent review of the new system in five years time against pre-agreed outputs, it should have had an opportunity to prove itself.

Where PPI Forums have worked well, it makes sense to build the new LINks on them, including their means of administrative support. When Forums were first set up after CHCs were abolished, there was a steep learning curve for PPI members. By building on the strong Forums some of the problems of the early days of PPI could be avoided. A measure of organisational stability is important where there are so many volunteers involved. It takes a great deal of time and effort by lay individuals to begin to understand the NHS. It is particularly important for the PPI organisations to have a collective memory given the transient nature of many health organisations and this is largely provided by the employment of professional support staff.

Why are existing systems for patient and public involvement being reformed after only three years?

I agree with the SHA who say it’s because Ministers like to give the impression they are doing something, and because it is now clear that the abolition of English Community Health Councils was an expensive mistake.

How should LINks be designed, including:

- Remit and level of independence.
- Membership and appointments.
- Funding and support.
- Areas of focus.
- Statutory powers.
- Relations with local health Trusts.
- National coordination.

The remit of LINks should extend beyond health to its wider determinants, as well as health and social care. It should be able to drill down to where the decisions are made, including being involved with the Practice-based Commissioning process.

If LINks are not perceived to be independent they will have no credibility. Under the present proposals the most obvious threat to their independence is their relationship with the sponsoring local authority, which will be responsible for managing the contract under which the support staff are to be employed. It is therefore important that the process of managing the contract is protected from political interference by establishing a transparent process and a fixed timetable—eg contracts should normally last for five years with perhaps a mid-term review, and any change should be agreed by the LINk, and not just by the local authority. As an additional safeguard, the contract should not be awarded to any existing group which enjoys major funding from the local authority concerned.

The concept of membership of a LINk needs to be defined, given that there are to be both individuals and organisations in membership. I hope that all lay people who have any sort of representative role in the arrangement of health or social care services in their area would automatically be a member of their local LINk. The Department of Health envisages a LINk as a network. It might be necessary to define a core membership in order to permit democratic decision making. I agree that there should be a requirement that every person who participates in the work of a LINk to be normally resident in the area of that LINk (although of course the work of a LINk may lead to investigation of services provided for their residents by organisations many miles away). I should also like to see a one-member-one-vote system for a LINk, whether the member is an individual or an organisation.

I think that membership should be entirely voluntary and self selecting as with Forums. This would mean that the collective voice of a LINk would have more weight than the voices of the individual members if it could demonstrate wider involvement, particularly of disadvantaged groups. The response of a LINk to consultation will be based on the experience and knowledge of its members. However, there will never be
sufficient resources to involve the wider public and the most disadvantaged people in every consultation. When LINks make official responses they should be required to state what processes informed the production of that response.

Many voluntary organisations will have financial interests in the provision of services in their area and it is important that these interests are declared and that these interests do not contaminate the voices of voluntary organisations representing their communities. Under previous legislation NHS employees and contractors were not allowed to be members of CHCs or Patient Forums. If such a prohibition is to continue then it should probably extend to any person with a financial interest in the provision of health or social care services in the area of the LINK. If the prohibition is abandoned (and even if it’s not) there will need to be a mechanism to register the declaration of interests. It will be very important that LINks adhere to the Seven Principles of Public Life established by the Nolan Committee and it will be necessary to ensure that there is some mechanism for dealing with complaints about this. There may be lessons to be learnt from the experience of the Standards Board for England.

LINks will need support from professional staff with experience in community development and of how the NHS and social care work. The staff will also need good IT skills. LINks need to be able to call upon skills training for its volunteer members to help them perform their PPI roles. It might be helpful for one organisation to support several LINks, perhaps calling on specialist organisations to deal with particular aspects of the work over a wide area. There needs to be organisational stability and a career structure if highly skilled staff are to move into this work. The staff should be accountable to the LINks whose members should be involved in any appointments.

I agree that funding should be directly related to population and not weighted for deprivation, rurality or any other factor. If there is a national budget of say £25 million for the population of England that works out as approximately 50 pence per head per year. Such a simple formula would make it easy to see whether the money is reaching its intended destination. If specific funding provision is made for particular sorts of deprivation or activity then this should be provided separately. Providers or commissioners should be allowed to pay LINks to conduct specific consultations or other projects on their behalf just as they often pay freelance consultants now, although the independence of the LINK should not be compromised. As an example, in our SW Oxfordshire Forum, we co-operated with the PCT in conducting “patient experience” and “food quality” surveys of patients in intermediate care after they had done their own survey, as an independent check (without payment).

LINks should have some statutory powers over and above the powers available to the public in general. In particular each LINk should have access to the detailed terms of any contract for the provision of health and care services to people in its area. Commercial confidentiality can be safeguarded by a provision making commercially sensitive information subject to confidentiality for a limited period. Nominated LINk representatives should have rights of access to health providers premises just as Forums do now.

If a national and regional organisation structure is set up to support LINks, then they must be answerable to the local LINks, and not the other way around. Members of LINks need to be enabled and encouraged to communicate with each other across the country so that specific wider issues can be addressed.

How should LINks relate to and avoid overlap with:

Local Authority structures including Overview and Scrutiny Committees

Overview and Scrutiny Committees’ effectiveness in relation to health varies very widely according to local political and geographical circumstances. I agree that there is potential for LINks and Scrutiny Committees to work together constructively, as we do in Oxfordshire. However in some local authorities the Scrutiny Committee is incapable of providing an effective challenge to service provision of indifferent quality. In such cases the LINks will need extra support.

Foundation Trust boards and Members Councils

As yet the impact of the democratic arrangements for Foundation Hospitals is difficult to assess. There is clearly potential for using those mechanisms to improve consultation and involvement of patients with hospitals and this may be useful for the relatively small number of people whose care is delivered primarily by a hospital. I hope that Members Councils would relate to their local LINK. However, I agree that the central political problem in health is the excessive political power and visibility of hospitals, particularly acute hospitals, as opposed to the invisibility of primary and community services.

Inspectorates including the Healthcare Commission

The efforts the Healthcare Commission and CSCI have made to date to involve patients in inspection arrangements are very encouraging and merit further development. The Commission could be a powerful ally in the development of involvement and it would be good if this role were strengthened. LINks should be recognised as working alongside the professionals in providing lay members for formal visits and inspections.
Formal and informal complaints procedures

The separation of complaints work from the work of Patient Forums has been a source of weakness as compared to the regime of the best CHCs where complaints contributed to a detailed picture of the performance of local health services. I understand that there are concerns about the confidentiality of complaints procedures but some mechanism must be devised to ensure that local LINks (or possibly some designated committee of a LINK operating on a confidential basis) have access to information about complaints which is sufficiently detailed to enable LINks to know which specific services give rise to complaints. There may also be a role for LINks to protect patients who complain as there are still widespread allegations of victimisation.

In what circumstances should wider public consultation (including under Section 11 of the Health and Social Care Act 2001) be carried out and what form should this take?

The proposed amendments to what is now section 242 of the National Health Service Act 2006 appear to envisage much more general consultation than has previously been required, and that is welcomed. I agree that decisions about the arrangements for consultation under section 242 should be made locally in conjunction with the local LINK which could take into account a wide range of factors, including the capacity of local communities to respond and the relative significance of various proposals. Consultation, to be effective, needs to take place much earlier—while the consideration of possible options is taking place. Those involved in their local LINK should not be surprised by the announcement of any proposal for substantial changes of service in their local area because they will have been involved at an early stage.

Jean Nunn-Price
January 2007

Evidence submitted by Len Roberts (PPI 74)

How Should the LINks be Designed?

Summary

The new system of LINks, as so far notified, has the capacity to either strengthen or weaken patient and public involvement in the NHS and the Social Services. Which way it goes will depend on the way the scheme is structured, its statutory powers, the extent to which it is professionally supported, and how it is promulgated.

Detailed Statement

1. An amorphous community network may act as a useful information resource for the Authorities, but unless it has a strong central Group of independent volunteers able to monitor services and enter directly into evidence-based debate, the public voice will be neutered. The current Patient Forums have developed such capacities: for example most Forums carry out formal and informal inspections, many Forum Chairs are non-voting members of PCT Boards, and Forum members join NHS committees and working groups. Their legitimacy to put a Patient Forum view is accepted.

2. The importance of a clear, cohesive and independent patient and public voice alongside that of clinicians, managers and financiers will be of critical importance as the service goes through a period of fundamental change.

3. Sometimes Patient Forums may not have been sufficiently in contact with, or representative of, the wider range of voluntary and community groups in their areas. A LINks scheme with a strong centre will strengthen the PPI system. A LINks system without a strong centre, will be a PPI system neutered.

4. Everything depends therefore on the structuring. There needs to be a strong central body in each individual area, made up of independent volunteers, with the legal authority to monitor services, be consulted and listened to on service issues and changes, and with the capacity to raise issues with the County OSC, and in any other way.

5. LINks should have a formal capacity in its relationship with the PCT. One possible way of structuring this would be for each PCT to have its own Patient Council drawn from LINks. LINks should also have formal rights in relation to the Strategic Health Authority and the Department of Health.

6. Where services are being provided at the County level, it should be remembered that patients and the public relate best to services in their own home areas. There is a danger of too much NHS centralisation. Within a County level PCT, there should be strong localities with their own budgets and management to which Locality Links can relate.
7. Weaknesses in the current Patient Forum system are often due to a failure to provide strong professional support. Volunteers have been asked to do a big job. They are not paid, and that is right. They do, however, have to spend a lot of time on computers, printing off documents, using the phone, travelling - and so on. They should receive a small but realistic allowance. If they are in work, they should (like Councillors) be entitled to a Financial Loss Allowance. They should not be expected to do administrative, managerial or technical research tasks. Some reports (for example of inspections) should be drafted by staff, for agreement. The bodies LINKS will be relating to have strong administrative support: statutory Patient Bodies should be entitled to no less.

8. LINks must have inspection powers to monitor effectively. Those carrying them out should be properly trained and professionally supported. They should not, however, be hedged in by detailed central regulations.

9. PPI has to look two ways: to be truly connected to its communities and equally to the services it monitors and be fully accepted as legitimate by both. It has to become part of the consciousness of the public and the staff, but his will not happen as by nature. LINks will need to be “branded”—and as a start have a name more descriptive of what it is about. The new brand should be publicised through the national media.

10. Patient and Public Involvement is a brave venture in strengthening democracy. The key issue is whether Parliament and the Government are serious in seeking a more civic society. If so, they could be more encouraging to volunteers. But above all they must provide the powers, and will the means.

Len Roberts
Chair, East Surrey Patient Group, a part of the Surrey Patients Forum
(comments are made as an individual)
9 January 2007

Evidence submitted by Peter Robinson (PPI 15)

INTRODUCTION

Until the end of December 2006 I was an interim Non-Executive Director of the North Nottinghamshire Teaching Primary Care Trust and had served on Ashfield Primary Care Trust as a Non-Executive Director for nearly six years. I also chair Central Nottinghamshire MIND and The Carers Council—Allies in Adult Mental Health. Over the last eight years I have been actively involved in the development of health services in the Ashfield and Mansfield areas, through these organisations but also through various carers strategic forums. I have experienced the difficulties of getting members of the public involved in health and social care service development. The PPI forums have played a very active role in trying to exert a patient and public influence which I have supported as a member of the PCT Board and through local consultations. I welcome the development of a structure which gives the patient and publics a more direct and flexible say in how local services develop and which holds the Primary Care Trusts to account for their performance.

My views on some of the questions posed in the Terms of Reference of the enquiry are below:

1. LINks representation on North Notts Teaching Primary Care Trust (PCT) should be two members, one for the North of the county (Ashfield, Mansfield, Newark & Sherwood) and one for the South (Broxtowe & Hucknall, Gedling, Rushcliffe).

2. LINks should link with the existing community health and social care forums in the county, and with existing regional forums. Membership of the LINk would be drawn from these groups which would include the existing PCT Public Focus committee, PALS, Ashfield Links Forum as part of the Local Strategic Partnership (LSP) and Mansfield Strategic Partnership, other Acute Trust and Mental Health Trust forums, and Practice Based Commissioning (PBC) Cluster group forums within the PCT area. It should also include representation from the following types of organisation in the PCT area:

   — Voluntary health and social care organisations.
   — Private health and social care providers.
   — Community organisations (Citizens Advice Bureaux, Sure Start, Womens Centre, Womens Institutes, Townswomens Guild, Hospital volunteering organisations, ethnic minority groups, etc).
   — Local government Overview and Scrutiny Committees.

3. LINks should provide flexible ways of engaging with the public rather than focus on meetings or committees. They should encourage the development of forums in PBC clusters.

4. The areas of focus of the LINk would be:
   — Obtaining the views of the public about health and social care services and feeding these back to statutory organisations (PCT and Adult Social care & Health) and the membership of the LINk.
— Providing a public voice in health and social care decisions on investment in care services and changes in services (and not just through the PPI representatives on the PCT Board).
— Ensuring that service commissioning structures involve the public in decision making, and that multiple commissioning organisations are effective in meeting public needs.
— Through an inspection function, monitor the quality of service provision and feed the outcomes of the inspection into PCT clinical governance processes and the LINk consultation processes.

5. Funding for the LINks should come through LSP’s.
6. LINks should be able to carry out their inspection function in any service, subject to individuals meeting the requirements of CRB or other checks (the document mentions Childrens services being excluded from inspection).

Peter Robinson
2 January 2007

Evidence submitted by Mike Tiernan (PPI 110)

1. Focus of this Response
   This response deals with the three initial broad questions posed by the Committee, and touches only briefly on some of the more detailed questions. The original consultation on the “Stronger Local Voice” proposal has already produced a wide response to many of the detailed issues but this Inquiry has introduced these three fundamental and very pertinent questions which the original consultation largely overlooked.

2. Source and Perspective of this Response
   The writer is a Mental Health Service User Involvement Coordinator employed by a PCT, with four years experience in this post and six years in a previous post as Service User Involvement Coordinator employed by a specialist Mental Health NHS Trust. The views are those of an individual, but are reflective of many people working in the field. The absence of any notification of this Inquiry through expected channels such as CSIP/NIMHE has precluded a collective response.

3. What is the purpose of patient and public involvement? Also, to what extent is it being achieved?
   PPI has several key purposes, with varying degrees of value, feasibility and success. The DoH sentence, “service users should be centrally involved in the evaluation, monitoring, design and delivery of services” includes two of the most important (evaluation and monitoring) plus two of the most difficult (design and delivery). Evaluation and monitoring are the most successful functions, but following through on rectifying deficiencies is more problematical. Design of services in true partnership with service users is in reality quite rare. Its feasibility is restricted by; the limited capacity (in terms of numbers) of service users motivated to be involved, power structures which are inherently (though usually subconsciously) not really receptive to it, and power structures working in a top-down system in which transformative decisions are the exception rather than the norm. Delivery of services by service users, although still very rare, is usually very effective, eg service user run crisis houses.

   Accountability to patient and publics, in terms of participation and transparency, has been successful at changing the previously endemic reluctance of organisations to disclose the motivations behind their decisions.

4. What form of PPI is desirable, practical and good value for money?
   In the context of mental health and some other specialities the soon-to-be dismantled system of independent PPI Forums covering a NHS Trust footprint fulfilled these criteria and should have been built on and extended, perhaps by linking the Forums to the relevant Overview and Scrutiny Committees. Setting up regional PPIFs with a statutory right/duty to report to the regional SHAs would have been an effective next step towards a national Forum.

   Many people working in the field regard this as a missed opportunity which will result in a “weaker local voice” and a continued absence of a regional or national voice for patients and public in mental health. The mental health perspective will be diluted by:
   (a) being subsumed by a generic Links Forum and a generic Overview and Scrutiny Committee; and
   (b) multiple smaller Links Forums which will have difficulty, and perhaps no incentive, in working together over a Trust footprint.
Building on the existing system would have been more effective and more cost effective than the new system. If the government persists in the new system, quite intricate, costly and burdensome linkages would need to be in place to retain the benefits of the previous system, let alone to improve on them.

Independent PPI Forums, working alongside other patient and carer groups, have had moderate success in spite of difficult circumstances. Mental health service user groups have long advocated for support in facilitating regional and national channels so that those many aspects of service design and quality which can only be influenced at a national level would have better, more regular and statutorily supported access to the real views and suggestions of service users. An opportunity to move closer towards that has been missed. Even acknowledging the one positive benefit of a statutory link to OSCs it is difficult to see how this proposal is even as good as “three steps forward and two steps backward”.

5. Why are existing systems for PPI being reformed after only three years?

Why indeed? Only the government can answer this, but the rationale in the “Stronger Local Voice” document does not present a cogent argument. The government’s continued emphasis on the local dimension, whilst perfectly legitimate, is often at the expense of the wider regional and national dimension, through which alone certain things can be changed.

Certainly, for evaluation and monitoring the local dimension is paramount, but for effecting significant change in service design the sub-regional and national arenas are crucially important. Ever since its inception patient and public involvement has suffered from fragmentation, but Trust footprint based PPI Forums were an effective step in the right direction. That step is about to be reversed and it is difficult to see how that can benefit even the generic acute hospitals services, let alone the mental health sector.

After a sustained period of increased investment in mental health it would have been wise to build on effective patient and public participation and scrutiny to ensure that money was achieving the desired improvements. The fait-accompli manner of consultation on this proposal (which asked basically how it should be done rather than asking whether or not it should be done) causes widespread perceptions of either ambivalence or poor judgement.

Mike Tierman
Voices in Partnership Coordinator
10 January 2007

Evidence submitted by Paul Brian Torey (PPI 47)

Introduction

1. I am giving evidence to the Health Committee from the realistic and mixed patient & public perspective of the longer term patient that has always needed a better more health giving mental health service. I will put forward some views on LINks by first demonstrating some evolved experience of current practice and its shortcomings which we will all need to guard against in the future. I am also someone who has served with the Birmingham & Solihull Mental Health Patient And Public Involvement Forum as a Deputy Chair and though I left that PPI in 2005 I have continued to work with it informally and provide it with information about the reality of the patient’s perspective In Birmingham. I have also continued to provide Dr Lynne Jones MP with information demonstrating patterns of poor Section 11 consultation in Birmingham regarding changes and services being varied in several Mental Health Day Centres in Birmingham.

2. I was more recently liaising effectively with the late Michael Elvin who died in December 2006. He was a Mental Health (MH) campaigner and previous Chair of the Birmingham & Solihull Mental Health Trust (BSMHT) PPI and he had provided some good evidence in October to November 2006 of evasion of Section 11 consultation with a concerning pattern of alteration, of an MH Day Centre service by increments over time, effectively driving away some patients.

These combined evidences and patterns have revealed real layers of flaws in the local practice of “modernising” policy that is desired by the Government. Dr Lynne Jones M.P. has more latterly, after meeting constituents, who have re-enforced claims of poor consultation and patient support, written to the BSMH Trust and asked them to improve their patient consultation practice and follow up, and demonstrate that more openly.

The BSMH Trust have been very slow to respond.
The Patient & Public Involvement Ethos And Supporting Patient’s Needs More Fully

3. Secretary of State for Health John Reid issued the words in 2003 that the Health Service should trust the patient.

“Trust me I am a patient”

4. Yet in both PPI terms and in ordinary experience terms of being a patient broadly, there has not been solid supportive cornerstones. It is not possible broadly to have more genuine democratic patient involvement rights as an MH patient until Patient Choice of treatments comes into being properly in the services that are currently overloaded with system Top-down approaches and more bureaucracies. I would urge the costs of those bureaucracies should be converted into more genuine therapy and marketised therapeutic community supports for patients as soon as possible. In one sense we need eventually less bureaucracy surrounding “Patient involvement” and more consumer demand-side democracy via Choice for the immediacy of proper patient involvement in health to take place.

5. Yet the Government has clearly seen MH as a way of socially engineering people back to work or “socially including them” yet the reality of this overapplied (by mistargetting) approach has in Birmingham, seen patients being uncoupled without choice from services despite PPI concerns. All along we the patients have seen a command and control approach both from the Government and the local Trust and other bureaucracies. On the PPI some of us were quickly aware that NIMHE bearing in on the services was hailed as an innovator but was changing into little more than an attempt to get people back to work before many had even had a treatment that actually fitted them towards more genuine “Patient led” recovery.

6. What some of us have seen is patients being sucked progressively into the “meetings culture” because both Trusts and NIMHE and other agencies have shaped “patient involvement” inside the pre-existing vacuous disempowering context of no “Patient Choice” and therefore into one of the pre-existing bureaucratic practice models ie meetings meetings meetings is all the game.

7. Suddenly empowerment was translated as “patients going to meetings” with planners and teams. This is frankly and eventually frustrating and quite crazing.

8. First and foremost medium and longer term patients need REAL Choices of treatments which fit them, are individualised, and are therapeutically supportive post-crisis so they can become the best socially creative shape that is possible without being sucked back into crisis cycles yet again. Secondly all need development grants for their needs. They don’t need meetings after meetings with planners and agencies.

9. Immediacy of support means Patient’s Choosing their health support packages and doing so locally where it fits them. That’s real involvement.

10. Being an MH patient on the PPI was very difficult as it was for other patient-colleagues because the Commission For Patient & Public Involvement In Health would only give a carer’s allowance so that someone could be alongside the patient-member at meetings I proposed to CPPIH as Deputy Chair, a special support group in late 2004-05 with the CPPIH region and said it should have some counsellors on it to help with the stress of being a PPI “mental health” member which was made additionally stressful because we were effectively monitoring our own Trust which in the main did not service the PPI mental health patient members well either. CPPIH responded to me by saying if the PPI was too stressing they would not recommend it. LINks I hope will support mental Health patients needs for those who get involved.

11. Whilst its true some instability is embedded in being an MH patient its clear this has to be treated as a disability factor and shored up appropriately with individual special group supports. A colleague on the PPI remarked that keen reflective knowledge by patient-members themselves, of what factors worsen intrinsic instability in the whole service context surrounding the patient, was a real asset strength of the PPI. Patient-members thus were seen to be indicators of realities. Yet poor supports by CPPIH undermined that asset strength and much of it was lost because of the additional stress on patient-members.

12. All new arrangements must look to the immediacy of what Patient Involvement has to mean. It has to mean patient power existing at the very GP and/or clinical gateway to services that fit them by PATIENT CHOICE. If CHOICE is avoided then we enter the mystification of tinkering with services (the meetings culture) and creating health bureaucracies to socially engineer “results” which are mystifyingly leaving many of us unsupported therapeutically. This is not a reality you can avoid from a patient perspective. It is where many of us live inside paradoxical arrangements or services that do not support our needs and which we are trying to alter in a double paradox of monitoring them.

LINks

13. LINks (Local Involvement Networks) are proposed for a future when at least some PPI’s were getting to grip with trying to democratise patient health services through statutory Section 11 Consultations. Apparently the Govt. believed the “pace of reform” was being slowed down by PPI’s insistence for instance on following Section 11 consultation practices. A DOH paper indicated that. So where is the implication of patient democracy in that? Are LINks a woolier way of watering down perceived opposition?
14. Where MH services are varied and that will affect health outcomes of those patients already in receipt of a service eg Mental Health Day Care Centres, then any consultations should backed by law and that power should be retained. Consultation should be seen to be done individually at Centres and transparently so and must be recorded otherwise local health officials will play games within this in a bid to secure an easier flow of apparent (rather than real) policy results from their management perspective. MH patients will suffer. That is what I have already observed The BSMHT PPI did so too in a 2005 “Impact Study” when following up patient experiences after service changes. With poor check and balance local bureaucracy dictates. The Local Trust also “buried” a PPI report from December 2004 to July 2006 which asked for the patient’s own voice of satisfaction to be recorded. The Trust quite cynically created a staff report about patients and said that was satisfactory. Therefore there has to be a robust power to monitor this kind of service-knows-best phenomena with LINks and it cannot be solely left to OSC’s. In Birmingham the task would be too much. On the other hand without the power of “Patient Choice” in MH we will not create effective patient-shaping of mental health but only a trend to deny the patients own voice of choice more insidiously under layers of new mechanisms. Consultation and “Patient Involvement” must go hand in hand more with “Patient Choice” too—all must increasingly re-inforce the other.

15. Thus LINks must retain an independent power to view in on what is happening in service areas where patients are affected by proposed variances of services. They would be a warning system that should both have the power to view in and refer matters to the OSC or even beyond to the Health Care Commission and Secretary of State.

16. The new Foundation Trusts Governor and Non Exec. member relationship with LINks I do not think can be anything but a co scrutiny view. But its also broadly a nonsense for MH patients to pretend “partnership” through proxies like Governors without the equalising “bottom- up” power of purchasing choice of health packages in MH, strengthened by LINks watching over matters and being patient- orientated. Foundation Trust arrangements with LINk’s have to keep looking at “bottom-up” patient led arrangements and securing their evolving reality. LINks have to have conjoined function with all involved to secure more “Patient Choice and led” services.

17. Duplication of functions here are actually notionally necessary otherwise the large Trusts can escape attentions on their performances because there is not enough people to do the scrutinising. It is to be hoped that this “bureaucratisation” is an transitory evolution towards patients controlling more of their own health packages and rendering “middle mechanisms and groups” about what they want more redundant in time.

Complaints Procedures

18. I am not convinced the Local Mental Health NHS should believe in the efficacy of its own complaint procedures which can be very conflict model driven still with MH patients in my experience. In fact there needs to be a beefed up ICAS which is accountable too to LINk’s. There ought to be recourse too to independent mediation with the State paying. I would not ideally use either the Trust’s complaints procedures or indeed its PALs services both of which are flawed locally and inspire no confidence at all in me. LINk’s should have the simple power to have local hearings about patient problems to take evidence too. They should augment OSC function as well as have freedom to report and express themselves.

19. ICAS as it shaped for MH in my opinion in Birmingham, does not inspire confidence locally and is weak. MH Advocacy itself in Birmingham is cherry picked for easier to deal with category groups and many, have overclose financial arrangements with the PCT’s or Trusts. Some patients and their problems also fall through geographic catchment nets of advocacy networks so ICAS needs to be strengthened. It needs to be retained and made stronger.

LINks Checks And Balances

20. A LINks body with an MH Sub Committee arrangement for instance, will almost certainly be made up of pre-existing relationships and would need some duties in law (to ensure the patient’s perspective) to balance out its inherent tendency to keep the local status quo Reform momentum in favour of the patient must create a way to challenge that. The PPI’s were notionally and somewhat Independent. The LINk’s may turn into a new body where local groups with favoured arrangements will support themselves within LINks without deeper authentic connection to patients. Some already claim a connection patients interests that is not completely valid. We have a “User Voice” in Birmingham (from 2002) where all ex users are Trust staff now and the local PPI is set to put forward a model for its independence (after a public & patient petition expressed the need) yet its clear the Trust wanted to dilute the patient voice into this “User Voice” mechanism it could handle, and that does not produce any stats on patient’s seen and solutions created.

21. Therein lies a problem of local health bureaucracy having too much power to arrange others apparent “voices” and that can feed potentially into a less than independent LINk’s body.

22. I feel the LINk’s must have the power to commission independent research therefore to performance review themselves in an honest manner—that must involve patient’s views locally without mediation by Trust professionals or staff.
23. LINks should be able to create their own visiting teams to go to see patient facilities and services otherwise we weaken the notion that the services are to be viewed accountably at a direct experiential and facility level. “Hand’s On” like this approaches are real to patients and will help confidence building in the process.

24. LINks must have the formal power to issue reports of concerns to whomsoever. This is a democracy and the bureaucracy in health is far outweighing the ability of the ordinary patient and public to create public accountability and due criticism.

Paul Brian Tovey
Independent Monitor Mental Health Matters
8 January 2007

Evidence submitted by Nora Warner (PPI 19)

I should like the following points to be added to the weight of evidence to be presented to the Health Committee. Although I am a member of Eastern and Coastal Kent PPI Forum and lead for Canterbury and Coastal Locality Group, these are my own views and do not necessarily reflect those organisations’ attitudes.

1. The purpose of patient and public involvement is to redress the balance. The NHS does not belong to the Department of Health nor to the staff. Ultimately it exists to serve the public who, through taxes, are its paymasters. It was high time they had a voice in decision making.

2. We bring a different perspective to plans and problems and are able to cite our own experiences as patients, carers or simply recorders of other members of the public’s views. Forum members devote many hours a week unpaid to PPI work. The only direct reward we get is to have our travelling expenses reimbursed. I don’t charge for phone calls or postage. I use my own stationery and IT equipment. We cover our own eating out expenses in order to attend meetings set at times that suit paid members of staff. We bring expertise acquired in other walks of life and we don’t complain if we aren’t even offered a glass of water, let alone a cup of coffee and a biscuit. I reckon that’s good value.

3. Who really knows why reform was felt to be necessary? Did Forums ask too many awkward questions? Our total independence meant we couldn’t be cowed or bullied. There have been claims that we are too white, too middle class, too old . . . who else has the time, the income and the experience to devote chunks of their free time to wading through lengthy and verbose reports; sitting through and making sense of countless meetings; instigating inspections; calling PCTs or Trusts to account; carrying out surveys; suggesting solutions to problems . . . We keep hearing about hard to reach groups who need to be heard. Any one thought that they may not want to be reached and have nothing to say?

4. I believe that there should be a PPI presence at every decision making level. To remind those who talk of beds that they are occupied by thinking, feeling human beings, who shouldn’t be moved about like chess pieces. To say and keep on saying: “But what will this actually mean for the patients?”

5. LINks (who thought up that excruciating name?) should build on the relationships forums have already established both with the public and their local NHS contacts. The big advantage will be bringing together social and health care under one “watchdog”.

6. They should be totally free from local authority interference. Funding should come directly from DoH.

7. No empire building.

8. Actually finding people willing to serve is likely to be a problem. One of the strengths of the original forum set up was that people felt they could influence what went on in their own patch. There is understandable reluctance to drive—in one’s own time—two or more hours to the other side of a local authority area, especially at night and in the winter. It takes a long time to understand how the NHS conducts itself—just ask the various Ministers who have struggled to get on top of their briefs. A pity if that hard won knowledge is thrown away.

9. It is vital that the forums’ statutory powers are retained by LINks. Surely we believe in openness and our inspections produce helpful suggestions as well as criticism.

10. The Healthcare Commission is on record as saying it wants a closer relationship with PPI, irrespective of whatever label it is currently wearing. Forums may be checking up on apparently small matters: distance to disabled parking bays; door width and ramp position; surgery opening times; telephone call charges; location of toilets; signage; menu choices and help with feeding . . . but ironing out such apparently minor inconveniences can make a great difference to the patient experience.

11. There was some resentment that forums apparently were seen as unpaid research assistants to OSCs. A better balanced partnership should be the aim, one that has some clout when it is needed.

12. Our forum has always been welcomed at PCT Board meetings. LINk representatives ought to have the right to offer their views and to vote when appropriate.
13. Our remit was not to take up individual complaints. Instead we became involved if a situation developed that affected a group of people. For instance, the closure of a clinic without warning or moving the out of hours access point without consultation. This seemed a sensible approach so that we did not overlap with the PALS service or patient user groups.

I hope these comments are useful

Nora Warner
3 January 2007

Evidence submitted by Mr John Wigley (PPI 104)

(a) **Purpose of patient and public involvement**

   It should be to open up the NHS to public scrutiny and have it react to expressed public needs.

(b) **What form of PPI?**

   Preferably quite small groups of people qualified by a combination of ability, interest and experience, who are representative; but not members of pressure groups.

(c) **Why change after only three years?**

   This is something for the Minister to answer. It seems to me that it was premature to announce that PPI Forums were to be scrapped after existing for barely a year.

(d) **How should LINks be designed, including**

   — Remit and independence. People linked to drugs companies and campaigning pressure groups and NHS employees should not be members.

   — Membership and appointment. There should be a formal and independent appointment procedure, to try to ensure suitability.

   — Funding and support. The Bill proposes to give funds to local authorities, but does not ring fence it—a major weakness.

   — Area of focus. Should be the whole local health economy-acute, PCT and full range of social services, plus ambulance and mental health.

   — Statutory powers. The PPI Forums had several important powers (the right to advise, inspect, monitor and to see information independent of the Freedom of Information Act), but the LINks will not have these powers- a serious weakness. NB It is being said that trained groups of LINks members will be given the power to inspect, but whereas PPI Forums had the right to inspect NHS premises plus premises of other bodies used by the NHS to provide services, LINks will not have power to inspect the latter, and so Surgi-centres (a growing part of the health economy) will be excluded—THIS IS A GREAT WEAKNESS.

   — Relations with Health Trusts. The LINks should have the right to send a representative to attend each Trust Board meeting, either as a full member with voting rights, a speaker or observer.

   — National Coordination. Absolutely vital to have a structure with independent funding from the Ministry.

(e) **How should LINks relate to and avoid overlap with Local authority structures including Overview and Scrutiny Committees**

   It is vital that LINks are not subordinate, but can have independent access to the health economy and Trust Boards, otherwise they will be stifled by local political inertia and in-fighting, achieve nothing and volunteers will leave, so PPI will come to an end. In my view, this is a distinct danger.

John Wigley
Deputy Chair, West Herts Hospitals NHS Trust PPI Forum
(Comments are made as an individual)

10 January 2007