House of Commons
Health Committee

Managing the care of people with long-term conditions

Second Report of Session 2014–15

Volume II
Additional written evidence

Ordered by the House of Commons
to be published 18 June 2014
The Health Committee

The Health Committee is appointed by the House of Commons to examine the expenditure, administration, and policy of the Office of the Secretary of State for Wales (including relations with the National assembly for Wales.)

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Powers

The committee is one of the departmental select committees, the powers of which are set out in House of Commons Standing Orders, principally in SO No 152. These are available on the internet via www.parliament.uk.

Publication

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.

The Reports of the Committee, the formal minutes relating to that report, oral evidence taken and some or all written evidence are available in a printed volume.

Additional written evidence may be published on the internet only.

Committee staff

The current staff of the Committee are David Lloyd (Clerk), Martyn Atkins (Second Clerk), Laura Daniels (Senior Committee Specialist), Stephen Aldhouse (Committee Specialist), Daniel Moeller (Senior Committee Assistant), Nathan Hug (Committee Support Assistant), and Alex Paterson (Media Officer).

Contacts

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1 Mr Stephen Dorrell was elected as the Chair of the Committee on 9 June 2010, in accordance with Standing Order No. 122B (see House of Commons Votes and Proceedings, 10 June 2010). The Speaker announced his resignation as Chair on 4 June 2014. On 10 June 2014 the Committee chose David Tredinnick to act as Chair of the Committee for all further meetings until a new Chair is elected by the House.
List of additional written evidence

(published in Volume II on the Committee’s website www.parliament.uk/healthcom)

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Written evidence

Written evidence from Arthritis Care (LTC 02)

INTRODUCTION

Arthritis Care is the UK’s leading organisation working with and for people with all forms of arthritis. People with arthritis are at the heart of our work. We have around 13,000 members, who are involved in all of our activities and direct what we do. We run a national telephone helpline and have a network of 190 local groups across the country, which together with our internet forums and self management programmes bring people together to support one another in living life to the full.

Arthritis is not only the most common MSK condition, it is the most common of all long term conditions, comprising 28% of the total, followed by heart conditions (16.8%). High quality and efficient arthritis healthcare services are essential to ensuring the NHS remains financially viable:

— Musculoskeletal conditions are now the fourth highest area of NHS spend.
— The cost of treating MSK conditions is rising rapidly, and has increased by 51.6% since 2003–04.

RESPONSE TO SPECIFIC ISSUES

The scope for varying the current mix of service responsibilities so that more people are treated outside hospital and the consequences of such service re-design for costs and effectiveness

A fundamental tool to delivering more out-of hospital care is risk profiling. Systematic involvement of patient organisations will help deliver smarter risk profiling, eg Arthritis Care, though our proposed “Arthritis Watch” project, will be conducting national mapping of need for, and shortfalls in, services.

There are also immediate savings that can be made by improving care for people with long term conditions (LTCs). For example, improved care for patients with bone and joint problems can reduce hospital stays and reduce inappropriate hospital referrals; hospitals in NHS Lothian have reported making savings of nearly £250,000, by speeding up the recovery time of such patients.

The readiness of local NHS and social care services to treat patients with long-term conditions (including multiple conditions) within the community

When addressing this issue it is helpful to consider what patient outcomes such a shift in services should deliver. Supported self-management (SSM) must be seen as a fundamental delivery goal of shifting care from hospital to community. Patients who are effectively equipped to self-manage and engage in meaningful shared decision making are able to achieve a better quality of life and become less of a burden on the system. There is evidence that even the most challenged patients can be encouraged to manage actively.

Over the past 20 years Arthritis Care has delivered over 1000’s of self-management training courses. We feel that we can bring our experience of working with people on self–management to bear to help shape and deliver SSM elements of the strategy.

The practical assistance offered to commissioners to support the design of services which promote community-based care and provide for the integration of health and social care in the management of long-term conditions

Assistance to commissioners must be based on a good understanding of the realities of commissioning LTC services. Recent research by the Nuffield Trust into commissioning care for LTCs has concluded that services for those with long-term conditions are not easily “commodified” within a purchaser–provider market. Local commissioners are not following the standard purchaser—provider commissioning model, but are developing an alternative approach based on closer working between providers and commissioners. The report highlights a number of factors that have helped deliver effective LTC commissioning, eg:

— A new way of sharing financial and service risk, where providers of care take on some or all of the commissioner’s risk, being responsible for assuring a set of services that will meet the needs of a particular local group of patients, such as the frail elderly, or vulnerable families.
— Regularly canvassing the views of local service users and providers about the performance of commissioners.

2 Department of Health, Programme Budgeting Data 2009–10, Available at: http://www.dh.gov.uk/en/Managingyourorganisation/Financeandplanning/Programmebudgeting/DH_075743#_2
3 Department of Health, Programme Budgeting Data 2009–10, Available at: http://www.dh.gov.uk/en/Managingyourorganisation/Financeandplanning/Programmebudgeting/DH_075743#_2
4 http://news.scotsman.com/edinburgh/Orthopaedics-improvement-saves-250k.6761205.jp
Ev w2  Health Committee: Evidence

— Regular survey of local clinicians about their involvement in commissioning and whether they think it is useful.

As well as addressing generic issues such as integration & self management, commissioners need to address LTCs from the perspective of how they can improve on a condition—specific basis. The services for each condition needs to be looked at to see how it can improve, offer better value for money, and integrate better with other services. The 3rd sector has a wealth of knowledge it can impart, at both a national and local level, of quality of existing services and levels of unmet need.

On a national level, condition—specific strategies can deliver impressive results. For example, the NHS
national heart disease and stroke strategy has in recent years delivered an track record of substantial improvements: heart deaths have been cut by half, with a similar level of success for stroke survival, the fastest improvement in Europe. This has been achieved by collaborative working in a number of ways: encouraging specialists to form local clinical networks; preventing unproductive competition between consultants, and concentrating specialist care.

These successes have only been possible with centralised strategic planning and a condition—specific focus, and provide a strong argument for a national MSK strategy which encourages similar coordinated ways of working for MSK services at local commissioning, regional and national levels.

The ability of NHS and social care providers to treat multi-morbidities and the patient as a person rather than focusing on individual conditions

Managing co-morbidities is one of the most significant challenges for a LTC strategy. Arthritis has strong links with other co-morbidities, eg cardiovascular and COPD. An Arthritis Care supporter recently described their experience of lack of coordination thus:

I am currently under the care of four different consultants at the same hospital & there appears to be great difficulty in having appropriate & timely communication between them & myself. If there could be one consultation involving all Specialists, say every three months, I would need fewer appointments are get better, faster care. As often one Consultant has to wait for the results or decision made by another Consultant.

Evidence from patient organisations such as National Voices shows what people most want is access to care coordinators who are able to arrange packages of care, ensure that specialist services are joined up, that patients are treated by the right people and in the most appropriate location. The care coordinator should be tasked with conducting “whole person” needs assessments at the beginning of an individual’s care pathway, and for collaborative care planning with patients. This role may be delivered by primary care nurses, but can also be done by trained and well supported volunteers; something Arthritis Care is piloting now. Care coordinators should also function as an “internal” patient advocate, arguing for patients when the system under-performs.

Current estimates put the number of LTC patient with care plans at 12%. Another essential component to dealing with co-morbidities is setting up generic multidisciplinary teams (MTDs), which aim to move away from single-disease silos of care and to stop patients falling through the gaps as they are shifted from GPs to social workers, outpatients, etc. Integrated teams do not have to work under the same roof, but they must meet regularly—in person or through teleconferencing—to review at-risk patients and jointly decide care packages. MDTs should comprise GP, nursing and therapy input, as well as case co-ordinators.

Obesity as a contributory factor to conditions including diabetes, heart failure and coronary heart disease and how it might be addressed

In addition to the conditions cited above, obesity is of equal importance to successfully tackling arthritis. There is evidence that increased services to promote lifestyle alterations would reduce the risk of developing osteoarthritis, eg strengthening exercises, general fitness, anti-obesity programmes and the use of supportive appliances. Up to half of all knee osteoarthritis is theoretically preventable by weight reduction and up to a third is preventable by preventative advice on activities that lead to joint injury, (ibid). A national nutrition strategy under Public Health England would be a way to address poor diet and over-eating, with direct attention paid to the role of the major food companies.

8 http://www.guardian.co.uk/commentisfree/2011/jul/29/david-cameras-nhs-competition
12 Standards of care for people with osteoarthritis, ARMA, 2005.
Current examples of effective integration of services across health, social care and other services which treat and manage long-term conditions

See the comment on multidisciplinary integrated teams in the section on co-morbidities.

When thinking about better coordination it is important to have an understanding of all the ways it should impact on services, particularly the need for improving the connections/interfaces between services, eg:

— Improve speed of referral to specialists, through co-location, specialist outreach clinics, etc.
— Improved handover systems, to prevent inappropriate medication or lack of treatment.
— Appropriate discharge and aftercare planning, to reduce “revolving door” patients.

These issues highlight the need for a variety of different types of coordination, eg parallel coordination between different care providers, and sequential coordination, ie the transfer of responsibility between healthcare professionals.

The ONEL project in Barking and Dagenham is an example of a joint health and social care project, aimed at meeting the needs of and maximising the quality of life for people with long-term conditions. A crucial element of its success has been gaining of detailed knowledge of the actual problems people in the area faced with their health and social care services. This highlights the need for commissioners to work out local solutions that are tailored to meet the needs of their areas, not just seek to impose “off the peg” examples of good practice.  

Torbay Care Trust is another oft-cited example of integrated health and social care, in this case, in respect of care for the elderly. Salient features include:

— Initially, the creation of an integrated health and social care team in 2004, which worked with a number of general practices to help older people most at risk.
— Use of care co-ordinators, who became the main point of contact for referrals, and worked closely with other professionals to put in place care packages.
— Creation of a care trust, which fully integrated NHS organisations responsible for commissioning and providing community health and social care services.

Key factors in delivering these changes included:

— Starting from the bottom up, by bringing frontline teams together and aligning them with general practices and their registered populations.
— A large measure of continuity of senior leaders and, until recently, much greater organisational stability than in the rest of England.
— Improvement has resulted mainly from the leadership of providers of health and adult social care services, with commissioners having a lesser role.

A drive towards greater marketization of services, with its corresponding increased fragmentation of services and staff churn, seem likely to substantially hinder, if not altogether preclude, attempts to integrate services along the lines of the Torbay model. (This factor is mirrored in the findings of the Nuffield Trust research, cited above, which similarly suggests the need for labour intensive long term relationship building between stakeholders in order to develop good LTC services).  

Another example of successful, integrated care services is the Pennine MSK Partnership, characterised by a single prime vendor holding one contract for all services within a specific pathway (in this case, MSK services).

The implications of an ageing population for the prevalence and type of long term conditions, together with evidence about the extent to which existing services will have the capacity to meet future demand

Whilst it would be inaccurate to consider arthritis a disease solely of the elderly, approximately half of the elderly population have arthritis. Expenditure on MSK conditions in general is increasing, in part as a result of an aging population: MSK spending has increased by 51.6% in the last six years, and is now the fourth-highest area of NHS spending.

There is mounting evidence of services for arthritis being restricted due to budgetary squeezes: people with arthritis already frequently report to us difficulty getting access to essential and timely services, eg assessment by specialist clinicians, physiotherapy. There are numerous reports of rationing of hip and knee surgery throughout the NHS, most recently from the Audit Commission. Given the projected increase in LTCs, it is  

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13 http://www.pulsetoday.co.uk/pcarticle-content/-/article_display_list/13604205/turning-the-personal-into-the-powerful
14 http://www.kingsfund.org.uk/publications/integrating_health_1.html
15 www.pmskp.org
17 Note, ARMA and other 3rd sector MSK bodies, including ourselves, strongly disagree with the report’s claim that hip and knee operations are “low value”: we argue that when viewed over the longer term delaying these operations is quite clearly a false economy: Audit Commission, Reducing spending on low clinical value treatments, (2011) www.audit-commission.gov.uk/sitecollectiondocuments/downloads/2010414-reducingexpenditure.pdf
difficult to see how existing services, frequently failing as they already are, could possibly in their current state with the projected increase in need.

The extent to which patients are being offered personalised services (including evidence of their contribution to better outcomes)

See the section on co-morbidities, above.

ADDITIONAL COMMENTS

A LTC strategy needs to make clear links with helping people with LTCs retain and return to work. The link between health and work has been increasingly recognised, particularly since Dame Carol Black’s 2008 Review.\(^{18}\) Arthritis and related conditions are the second most common cause of days off work.\(^{19}\) With government funding, Arthritis Care has worked with stakeholders to produce an online work retention toolkit for people with long-term fluctuating conditions and their employers.\(^{20}\) The strategy could reference this resource, and seek to build on it.

13 May 2013

Written evidence from the British Acupuncture Council (LTC 03)

BACKGROUND

1. The British Acupuncture Council (BAcC) regulates and represents the 3,000 traditional acupuncturists in the UK. Entry to the BAcC is gained after at least three years of formal degree-level training.

   BAcC members support the health and wellbeing of people across the UK, giving over 2.3 million treatments a year.

   This year the BAcC gained accreditation from the Professional Standards Authority (PSA—formerly the Council for Healthcare Regulatory Excellence) as part of our continued efforts to strengthen the regulation of acupuncture.

SUMMARY

2. There is scope for an improved mix of services providing care for people with long term conditions—in particular using professional therapists such as acupuncturists, so that more people are treated outside hospital. British Acupuncture Council acupuncturists are degree level trained and provide services within local NHS and social care services.

   Commissioners need to design services which promote such community-based care. BAcC Acupuncturists can treat multi-morbidities and the patient as a person rather than focusing on individual conditions. Patients with long term conditions treated by BAcC Acupuncturists are offered personalised services that should be recognised.

   It is recommended that NHS contract and commissioning mechanisms such as QOF and QUIPP recognise long term conditions. Service specifications should recognise Acupuncture to support people with long term conditions.

   Pilots should be established to test models of improving practice.

3. There is a significant evidence base for acupuncture that should be recognized within this field—with National Institute of Clinical Excellence recommendation for chronic lower back pain, for headache and a recent “meta analysis” of over 18,000 patients also demonstrated that acupuncture is beneficial for chronic pain.

4. Patients with long term conditions should be able to exercise choice of treatment in their long term condition and receive world-class treatment. Acupuncture offers personalised healthcare that demonstrably improves health and wellbeing outcomes for patients with long term condition.

5. The demands of a long term conditions mean that fundamental change is needed. The British Acupuncture Council argues that it is time to think differently about how to respond to the future health challenges facing the UK.

6. BAcC would like to make the following suggestions:

   — Greater choice for people with long term conditions—for too long, debate about health has been trapped on narrow ground, in debates about the NHS. The BAcC wishes to change the debate by asking what people with long term conditions want from a 21st century health and care service. It’s clear from the four million of treatments a year for acupuncture, that the public wish to choose services such as acupuncture.

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18 \[http://www.dwp.gov.uk/docs/hwwb-working-for-a-healthier-tomorrow.pdf\]
19 Arthritis: The Big Picture, ARC (2002)
20 \[http://www.arthritis.org.uk/LivingwithArthritis/Workingwitharthritis\]
— Evidence based cost effective services—Acupuncture can provide cost-effective results for people and families. There is NICE guidance recommending acupuncture as a cost-effective option for lower back pain (also for headache). Acupuncture avoids a pharmaceutical based approach, with little or no side effects.

— Quality care—Acupuncture provides the holistic, quality care that people want—and demonstrate they need.

10 April 2013

Written evidence from The Royal College of Radiologists (LTC 04)

1. The Royal College of Radiologists (RCR) has over 9,000 Fellows and members worldwide, representing the specialities of clinical oncology and clinical radiology. The role of the College is to set and maintain the standards for entry to and practise in these specialities, in addition to leading and supporting practitioners throughout their career.

2. The Royal College of Radiologists has outlined in this submission those issues of relevance to our specialities regarding long term conditions.

The scope for varying the current mix of service responsibilities so that more people are treated outside hospital and the consequences of such service re-design for costs and effectiveness

3. From the perspective of clinical radiology, we would strongly agree with this as a mechanism for improving both quality of life and cost effectiveness. We believe that clinical radiology could help facilitate this by providing more effective diagnostic support to primary care.

4. From the point of view of clinical oncology, long term conditions impinge on patients in two main ways:
   (a) Long term conditions that cancer patients have and which need still to be managed during their active cancer treatment.
   (b) Long term conditions which patients develop as a result of treatment, such as chronic radiation change in bowel, lung fibrosis and peripheral neuropathies.

5. For some patients, both pre-existing long term conditions and those developing following treatment, are multiple and the resulting problems complex. The current mix of service responsibilities is not adequate for these patients and they require the setting up of new services which have been started for some problems such as chronic bowel problems. The interdependence of a number of different long term conditions makes management difficult but this is an initiative which the survivorship programme is trying to address. Within this social care is an important part.

6. The success of cancer treatments means that there will be an ever increasing group of survivors whose quality of life needs to be enhanced by effective management of the consequences of treatment and it is hoped that this scenario will find a valid place within the commissioning framework.

1 May 2013

Written evidence from Together for Short Lives (LTC 05)

ABOUT US

Together for Short Lives is the leading UK charity for all children with life-threatening and life-limiting conditions and all those who support, love and care for them. We support families, professionals and services, including children’s hospices. Our work helps to ensure that children can get the best possible care, wherever and whenever they need it.

Children’s palliative care (CPC) differs greatly from adult’s palliative care. Whereas the majority of adults only need palliative care at the end of their lives, children with life-limiting and life-threatening conditions require palliative care over a much longer period, often from birth. It is common for their conditions to fluctuate and, as such, it is often much more difficult to identify when a child is moving into their end of life phase. Children with life-threatening and life-limiting conditions often have complex disabilities, while the range of health conditions which results in children requiring palliative care is more diverse.

To cite the committee’s definition of a long-term condition, many children who need palliative care have conditions which “cannot, at present, be cured, but can be controlled by medication and other therapies”.

We welcome this opportunity to comment on the management of long-term conditions in England. We would be happy to provide oral evidence if requested to do so.
Summary of our Submission

— When a child who has a life-threatening condition reaches the terminal phase of their illness, the preference for both the child and family is usually to die at home in familiar surroundings. However, a majority of children aged 19 and under suffering from conditions likely to have required palliative care (excluding neonates) die in hospital.

— There is greater scope for treating young people who need palliative care outside of hospital settings through children’s hospices and other types of community care. These services represent a more cost-effective approach to CPC and can reduce costly, unplanned emergency admissions to hospital.

— There are examples of existing good practice: in some areas, community children’s nursing teams carry out the majority of care to children and young people in the community. This includes the more day-to-day aspects of children’s palliative care. Some children’s hospices also provide a “hospice at home” community model of care.

— Poorly planned transitions between children’s and adult’s services mean that many young people with life-threatening and life-limiting conditions face a “cliff-edge” when they reach adulthood; community services must be commissioned effectively to provide integrated palliative care to young people.

— **Together for Short Lives** is working with the Department of Health and NHS England to develop guidance for Clinical Commissioning Groups (CCGs) to help them commission CPC services. This guidance will promote community-based, integrated care.

— Providers of CPC, including children’s hospices, have a strong record of providing person-centred care to children, young people and their families. Approaches such as key working can help to join up care for children and young people.

— The Government’s proposed reform of special educational needs and disability policy has potential to join up education, health and social care for children with life-threatening and life-limiting conditions. However, as the reforms currently stand, only children with special educational needs will benefit from the reforms. We believe that this is a wasted opportunity.

— There is a strong link between CPC and mental health and social/economic wellbeing in terms of the impact on families who care for children with life-threatening and life-limiting conditions.

Our Submission

*The scope for varying the current mix of service responsibilities so that more people are treated outside hospital and the consequences of such service re-design for costs and effectiveness*

1. Universal, targeted and specialist CPC is provided by a web of providers. Generalised CPC services may be commissioned from the whole range of the statutory and voluntary sectors using collaborative commissioning arrangements. At all times, locally available and community-led CPC should be at the heart of provision to children and young people.

2. There is greater scope for treating young people who need palliative care outside of hospital settings through children’s hospices and other types of community care. These services represent a more cost-effective approach to CPC and can reduce unplanned admissions to hospital.

3. Effectively commissioned and provided CPC can play a cost-effective role in supporting early discharge for children and young people from acute care settings through step-down care. It can also help to reduce unplanned admissions among children and young people to acute care settings. The Government-commissioned funding review highlights estimates that hospital admissions in the last year of life for children who need palliative care cost £18.2 million. This far outweighs the cost of providing palliative care outside of the hospital setting. Research has also shown that short breaks provided by children’s hospices—which may include healthcare interventions—help to reduce stress on families and demand on public services.

4. Evidence submitted by **Together for Short Lives** to the committee’s recent inquiry into the implementation of the Health and Social Care Act 2012 demonstrates the wide variation in the extent to which PCT clusters, clinical commissioning groups (CCGs) and local authorities commission children’s hospices to provide CPC. In order for more CPC services to provided outside of hospital, commissioning organisations must provide fair and sustainable funding to a range of providers across the statutory and voluntary sectors.

*The readiness of local NHS and social care services to treat patients with long-term conditions (including multiple conditions) within the community*

5. When a child who has a life-threatening condition reaches the terminal phase of their illness, the preference for both the child and family usually to be able to die at home in familiar surroundings. However, in 2007 a

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6. The ability of community services to treat young people with life-threatening and life-limiting conditions varies between local areas. In some areas, community children’s nursing teams carry out the majority of generalised CPC with input from specialist health professionals. The Together for Short Lives care pathway describes the CCN services required as part of comprehensive CPC.

7. A Department of Health report of its review of community children’s nursing cites the example of the Diana team, which part of Newham community health and care service. The Diana team is a nurse-led multidisciplinary team established in 2006, based at Richard House children’s hospice. It works in partnership with the hospice to deliver community palliative care for 0–19-year-olds, including children with long-term ventilation needs. The team focuses on respite, symptom control management and end-of-life care. The team also includes a clinical psychologist, play specialist co-ordinator and a team of healthcare support workers.

8. During 2009–10 the Diana team had a caseload of approximately 40; 10 children received end-of-life care. The local children’s integrated commissioner invested in the service, increasing the workforce by 100%. The Diana team’s key achievements include:

   (a) Keeping children with complex healthcare needs, including long-term ventilated children, out of hospital.
   (b) Planning and co-ordinating end-of-life care, ensuring that choice of place of death is offered.
   (c) A considerable increase in productivity year on year, especially in the area of new referrals, as clinical professionals become more confident in the expert delivery of palliative care—including end-of-life care; and
   (d) Establishing a play service offering therapeutic play in the child’s home.

9. Some children’s hospices also provide a “hospice at home” community model of care, where hospice medical and care staff provide an outreach service, supporting families in caring for their children at home.

10. Poorly planned transitions between children’s and adult’s services mean that many young people with life-threatening and life-limiting conditions often face a “cliff-edge” when they reach adulthood. In some areas community children’s nurses will only care for young people up to the age of 16. Where this is the case, care should transfer to district nurses. However some district nurses will not provide palliative care to young people aged 16–19 unless commissioned to do so by their CCG. Many young people and families who find that their transition from children’s to adult services is marred by a lack of communication between local providers and a struggle to secure the care they need.

The practical assistance offered to commissioners to support the design of services which promote community-based care and provide for the integration of health and social care in the management of long-term conditions

11. Together for Short Lives is working with the Department of Health and NHS England to develop guidance for Clinical Commissioning Groups to help them commission CPC services. The guidance will advocate community-based, integrated care for children with life-limiting and life-threatening conditions.

Current examples of effective integration of services across health, social care and other services which treat and manage long-term conditions

12. There are some good examples of integrated health and social care services for children who need palliative care, as case of the Newham Diana team cited in paragraphs 9 and 10 demonstrate. Providers of CPC, including children’s hospices, have a strong record of providing person-centred care to young people and their families. In some local areas, the NHS and the local authority jointly commission children’s palliative care together.

13. More widely, however, Together for Short Lives believes that the separate health and social care commissioning systems make it difficult for providers to treat the person rather than their condition(s).

14. The Government’s proposed reform of special educational needs and disability policy—set out in the Children and Families Bill—has potential to better integrate education, health and social care for children who need palliative care. However, as the reforms currently stand, only children with special educational needs (SEN) will benefit the more joined-up services that the single assessments and Education, Health and Care Plans that the Bill proposes. 25% of young disabled people do not have SEN.

15. Local authorities will also not be duty-bound to undertake the single assessments and to put a plan in place if a young person is over the age of 16 and not in further education or training. This is a missed opportunity.

opportunity—Together for Short Lives calls for all young disabled people between the ages of 0 and 25 to have access to joined-up assessments and services, regardless of their educational status.

16. Key working approaches to providing services can lead to more integration for children and young people. Key worker support provides a system-navigator who aims to ensure holistic care and support to meet the individual requirements and aspirations of the child and their family. The care and support they provide is family centred, not only child-centred.

17. A recent paper from the National Children’s Bureau summarises the key evidence and consistent elements of a key working approach. It also analyses the implications of key working in health, social care and education. The Government is testing the key working approach as part of its special education Needs and disability (SEND) pathfinder programme. An interim report of the programme’s progress highlights some positive progress in terms of key working achieving better outcomes for disabled children.

The interaction between mental health conditions and long-term physical health conditions

18. There is a clear link between CPC and the mental health of families who care for children with life-threatening and life-limiting conditions. Families may feel particularly vulnerable when it has been established that their child has long-term palliative care needs. Unrealistic expectations not discussed with the family on discharge from hospital following initial diagnosis and treatment can lead to increased feelings of isolation, exhaustion, stress or depression. Family relationships are also put under stress in caring for a child with a life-threatening and life-limiting condition. It is important that short breaks are provided for families as part of a comprehensive palliative care service.

19. It is important that bereavement services are in place for parents, siblings, grandparents, other family members and friends—all of whom will have different care needs—during the child’s illness and following their death.

The extent to which patients are being offered personalised services (including evidence of their contribution to better outcomes)

20. Providers of CPC, including children’s hospices, have a strong record of providing person-centred care to young people and their families.

21. We know from evidence that a disjointed system of care presents many challenges for families of children with life-limiting conditions. These families routinely deal with over 30 professionals from education, social care, health and other services. Communication between agencies is generally inadequate, leaving families burdened with the stress of navigating their way through an uncoordinated system.

22. This experience is common among families of disabled children. However, for families whose children’s lives are likely to be short, time wasted navigating through the system in this way can be particularly distressing.

9 May 2013

Written evidence from the British Heart Foundation (LTC 06)

SUMMARY

— The BHF is currently providing support for projects aimed at treating more patients outside hospital.
— Cardiac rehabilitation is a model of long-term condition management that needs to be fully funded across the UK. Every patient who is suitable and wishes to take part should be offered a cardiac rehabilitation programme.
— Every person living with a long-term condition should be guaranteed a holistic needs assessment, a written care plan encompassing health, social and preventative care and the right to access a named care co-coordinator of their choice.
— To ensure that patients benefit from all the latest developments, Health Education England should recognise the importance of continuing professional development of specialist nurses and other healthcare professionals.
— Every person with a long-term condition should be treated for their physical and psychological needs in equal measure.
— A number of measures are needed to tackle obesity and create an environment that helps people to make healthier choices on food and increase levels of physical activity.

— We believe the Committee should also separately consider the contributing role of tobacco as major contributing factor to the development of long-term conditions.

1.1 The British Heart Foundation (BHF) is the nation’s leading heart charity. We are working to achieve our mission of a world in which no-one dies prematurely of heart disease. There are 2.3 million people in the UK living with coronary heart disease and in the fight for every heartbeat we want to ensure they have all the support they need to manage the impact of their condition of all aspects of their everyday lives.

1.2 We welcome the opportunity to respond to the Committee’s inquiry on how the NHS and social care system in England supports people with long-term conditions such as heart disease. It is disappointing that after seeking views on the development of a new long-term conditions strategy last year the Department of Health has opted not to publish a strategy. While NHS England now has the responsibility to take this forward, we believe that strong recommendations from the Health Committee may help to ensure that making tangible improvements for people with long-term conditions is prioritised.

1.3 The Department of Health originally set up a cross government group to develop the strategy, in recognition of the many different areas of people’s lives that may be affected by having a long-term condition. While NHS England takes this work forward alongside relevant organisations in the new commissioning landscape, it is important that cross-government involvement continues.

1.4 We are pleased to see the Committee review as part of the inquiry services provided for patients with diabetes as having diabetes, especially if it’s undiagnosed or poorly controlled, can significantly raise your risk of having a heart attack. While the Committee has also asked for evidence on obesity as a contributing factor to long-term conditions, we believe the Committee should also separately consider the contributing role of tobacco—which is responsible for around 25,000 deaths from cardiovascular disease each year.29

TREATING PEOPLE WITH LONG-TERM CONDITIONS IN A COMMUNITY SETTING

2.1 The Committee has asked for comments on varying the current mix of service responsibilities so that more people are treated outside hospital. The BHF is currently providing support for projects aimed at treating more patients outside hospital. For example, we are currently funding a two-year pilot programme to assess safe and effective ways for specialist nursing teams to administer intravenous (IV) diuretics to people at home, or in a day care setting, with the view to preventing costly hospital admissions.

2.2 People with heart failure often experience breathlessness and as the condition worsens, fluid accumulates in the lower limbs, and eventually in the abdomen. Diuretic tablets help reduce fluid retention, but as the disease progresses, oral diuretics are not enough to control symptoms. To relieve symptoms at this stage, the patient is currently admitted to hospital and treated with IV diuretics.

2.3 The BHF pilot supports heart failure specialist nurses at twelve NHS sites in the UK, and help them develop and introduce community based IV diuretic services as part of existing heart failure services. Following guidelines developed by a BHF-led steering group and expert panel, specialist nurse teams are trained to administer the IV medication safely and effectively out of hospital, to closely monitor the patients’ response to treatment, and adjust dose as necessary.

2.4 Challenges during the development of the project have included gaining support from other parts of the healthcare system, securing backfill staffing for the project lead and providing a seven day and out of hours service.

2.5 In addition to the twelve funded projects, there are six extra sites that are not part of the award but are participating in the on-going, independent evaluation of the project. Every site will deliver care to heart failure patients slightly differently, by integrating this new aspect of patient care into existing local services. The evaluation will report on the effectiveness of each service and a final evaluation will be available in late 2013. The interim report has already been published and is already demonstrating impacts and outcomes.30

2.6 If successful, this project will allow the specialist teams to develop new best practice guidelines and protocols for community-based IV diuretic treatments that can be rolled out on a wider scale. Administering IV diuretics in community settings should help increase patients’ quality of life and reduce hospital admissions.

EFFECTIVE MANAGEMENT OF LONG-TERM CONDITIONS

3.1 Cardiac rehabilitation has been defined as the sum of interventions needed to ensure the best possible physical, psychological and social conditions for heart patients. Most heart patients need support to help them live with their condition and to prevent a further major heart event.31 Recent developments in the treatment of heart disease, such as thrombolysis and primary angioplasty, have changed the experiences of heart patients and dramatically reduced their residual cardiac impairment. Consequently some patients do not perceive themselves to be in need of further help and support. For most patients with heart disease, the focus of cardiac

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30 Brightpurpose. *Evaluation of home-based IV diuretics pilot: interim report for the British Heart Foundation*; 2012. Available at: www.brightpurpose.co.uk
rehabilitation programmes now is therefore on helping people living with heart disease to manage their condition and to prevent that condition from deteriorating. Cardiac rehabilitation is therefore a model of long-term condition management.

3.2 Cardiac rehabilitation can take place in hospital as an outpatient, in a community setting such as a GP practice or sports centre or in the patient’s own home. Some patients like a group-based programme but others do not and prefer to carry out their rehabilitation at a time and place that suits them and their family. There is evidence that offering a home-based self-management programme as an option can substantially improve uptake and that outcomes from these programmes are the same as those from traditional group-based programmes. Importantly, offering patients a choice may increase take-up of services especially amongst groups who are currently under-represented as they may face practical problems accessing centre-based programmes.

3.3 NHS Improvement commissioned a short study in 2013 that modelled the relationship between uptake of cardiac rehabilitation and unplanned cardiac readmission rates both nationally and at commissioner level. This aimed to examine the Quality, Innovation, Productivity and Prevention (QIPP) potential of cardiac rehabilitation and to establish whether the benefits of cardiac rehabilitation outweigh the costs in terms of the potential impact on readmissions alone.

3.4 The results suggested that increasing the uptake of “gold standard” cardiac rehabilitation has the potential to reduce cardiac-related readmissions and deliver significant financial savings. Achieving an uptake rate for cardiac rehabilitation of 65% in England among all eligible patients could reduce admissions by over £28,000—releasing over £30 million per year in overall savings nationally which could be reinvested in rehabilitation and re-ablement.

3.5 Cardiac rehabilitation has been identified by national governments, the health service and NICE as an important part of the care that should be provided for people with heart disease, yet provision and take-up remains patchy across the UK. This is in spite of it being a cost effective programme, costing around £550 per patient to deliver. According to the latest figures from the 2012 National Audit for cardiac rehabilitation just 44% of heart patients in England took part. Cardiac rehabilitation services need to be fully funded across the UK. Every patient who is suitable and wishes to take part should be offered a cardiac rehabilitation programme.

3.6 The Department of Health in England published a new Cardiovascular Disease Outcomes Strategy in March 2013. The Strategy has highlighted that care providers should carry out a holistic assessment of the patient’s need for rehabilitation and long-term support, which should consider the physical, psychological and social care needs. A specific action in the Strategy is therefore for NHS Improving Quality (which from April 2013 replaced NHS Improvement) to work with the new Strategic Clinical Networks in England to develop, evaluate and disseminate approaches to assessment and care planning for CVD patients—including the full cardiovascular assessment. This would be strengthened further through a long-term conditions outcome strategy produced by NHS England, which would reiterate the importance of rehabilitation, and call on commissioners to ensure that cardiac rehabilitation is available to all heart patients who choose to take part.

PATIENT-CENTRED INTEGRATED CARE

4.1 People with long term conditions, such as heart disease, often have numerous, confusing and uncoordinated interactions with the health system and social care systems. Typical problems include dealing with a range of different healthcare professionals who do not have access to existing medical records or other information, poorly scheduled appointments and a lack of clarity about who to contact for advice and support.

4.2 We have included in appendices 1 and 2 the health care journeys of two patients that have shared their experiences of how they have interacted with different services related to their care (anonymised for this submission). They illustrate the complexity of different services that patients are required to navigate. These “webs of care” suggests a system that has not been built around the patient.

57 www.nice.org.uk/usingguidance/commissioningguides/cardiacrehabilitationservice/
4.3 To effectively provide for the integration of health and social care in the management of long-term conditions, every person living with a long-term condition should be guaranteed a holistic needs assessment, a written care plan encompassing health, social and preventative care and the right to access a named care co-ordinator of their choice. The process of developing the care plan should help people understand the care and support that they are receiving and be confident about who should be approached if they need support. Further information is detailed in the report From vision to action, produced by the Richmond Group of Charities—a coalition of ten of the leading health and social care organisations in the voluntary sector.40

4.4 The BHF is a member of the Care and Support Alliance, a group of over 70 organisations who support and represent older and disabled people, those with long-term conditions and their families. We believe that the social care system is in crisis—unable to cope with a rapidly ageing population and people living longer with illness and disability. Urgent reform and additional funding are therefore essential.

IMPROVEMENTS TO STAFFING

5.1 It is vital that the right workforce is in place to best meet the needs of people living with long-term conditions. In particular, there needs to be adequate investment in specialist nurses. The value of these posts has been demonstrated in recent years, including through the BHF’s investment in specialist cardiac nursing. Between April 2009 and March 2011, BHF heart failure nurses reported that they were responsible for avoiding 19,555 unplanned hospital admissions. This saved the NHS around £34.5 million.41

5.2 Where specialist nurses are in post, they need the resources and capacity to be able to train and support other healthcare professionals in their locality to meet the needs of patients in the community. It is likely that a significant number of patients will be seen by generalist community health professionals, given the prevalence of cardiovascular disease. The BHF currently funds innovative new roles to increase levels of education in primary care. Our Improving Knowledge, Improving Care project specifically aims to optimise care and outcomes for patients who have had a heart attack and those with heart failure, in order to reduce regional disparities in standards of care and management of treatment. This will be achieved through delivering education to primary and community-based healthcare professionals, including GPs and practice nurses, in six pilot regions.

5.3 Specialist nurses are an important part of the infrastructure to support people living with long-term conditions. Generalist health professionals need appropriate training and support to ensure that they are also able to best meet the needs of these patients. To ensure that patients benefit from all the latest developments, Health Education England should recognise the importance of continuing professional development of specialist nurses and other healthcare professionals.

MENTAL HEALTH

6.1 People with long-term conditions also have significant psychological and social needs. Long-term conditions coupled with depression are a significant and growing challenge for health and social care services. People with long term conditions are twice to three times more likely to experience depression and estimates suggest that 20% of people with long term conditions have depression.42

6.2 Depression is two to three times more common in a range of cardiovascular diseases and studies indicate that depression can increase the cost of managing long-term conditions by between 33–169%. Every person with a long-term condition should be treated for their physical and psychological needs in equal measure.

TACKLING OBESITY

7.1 The Committee has asked for evidence on how to address obesity. As highlighted by recent policy reports in the UK, obesity remains a serious and pressing issue that requires wide-ranging measures to tackle in full.53,44 According to the Health Survey for England 2009–11, one quarter of men and women are obese (BMI over 30) and two thirds of adults are obese or overweight (BMI over 25). Getting and keeping to a healthy weight can reduce your risk of not only heart disease but a number of other health problems, such as diabetes, some cancers and arthritis.

7.2 A healthy diet is one factor that can help to ensure fewer excess calories in addition to other measures such as regular physical activity. But in order to make healthy choices on what we eat, we need an environment that helps people to make healthier choices. We are encouraged by recent progress on food labelling, and are hopeful that the Department of Health will soon recommend a single front-of-pack traffic light scheme that will be adopted by all major retailers, helping people to make healthier at-a-glance choices based on the

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40 www.richmondgroupofcharities.org.uk/
41 This estimate is based on a tariff cost of admission per patient of £1,826. This tariff was used in a 2008 evaluation of heart failure specialist nurse services BHF (2008). The development and impact of the British Heart Foundation and Big Lottery Fund heart failure specialist nurse services in England: Final report April 2008
42 BHF et al (2012). Twice as likely: putting long term conditions and depression on the agenda.
43 Royal College of Physicians. Action on obesity: Comprehensive care for all; 2013
44 Academy of Medical Royal Colleges. Measuring up: the medical profession’s prescription for the nation’s obesity crisis; 2013
nutritional content of the food they are buying. We also believe that more needs to be done to address the variability and growth of food portion sizes and plan to publish a report on this issue in the summer.

7.3 Obese children are more likely to become obese adults, and we believe a number of measures are necessary reduce their exposure to promotions for processed foods and drinks high in fat, saturated fat, sugar, and salt. We need a system that truly protects our children and young people from sophisticated marketing campaigns and believe the Government should move to:

— end to junk food marketing before 9pm; and
— better protect children from the influence of non-broadcast junk food marketing.

7.4 A BHF report produced in 2011 reveals the tactics companies are using to market to our children online and assesses how brands bombard kids online in a bid to push products that are high in fat, salt and sugar.45

7.5 Evidence shows that children who are physically active have a better chance of becoming healthy adults, yet a significant proportion of children are not reaching recommended levels of activity.46 Regular activity reduces the risk of obesity in adulthood and reduces the likelihood of risk factors for chronic diseases, such as heart disease and type 2 diabetes, developing early in life.47 Only one in ten children in England can correctly recall the need for 60 minutes of daily physical activity and half of UK parents underestimate how much physical activity their child needs to maintain a healthy lifestyle. Sustained communication at population and individual level is needed to improve understanding.

7.6 Schools also need to maximise the opportunities for children to take part in physical activity during and around the school day in a positive and inclusive environment. Children should be encouraged to participate in extracurricular physical activities, to be physically active at break-times and to walk and cycle to school.

7.7 With the transfer of responsibility for public health issues in England to local government, local authorities are now well placed to ensure that decisions regarding planning, transport and education support increases in physical activity. Public Health England also needs to lead this approach strategically.

9 May 2013

APPENDIX 1
Ev w14  Health Committee: Evidence

For me, and many others that I have spoken to, there is one VERY simple and relatively inexpensive that the NHS could do that would make a HUGE improvement for us patients — give doctors and nurses more training on needle skills — how to take blood and fit cannulas etc.

I was treated at loads of different hospitals but my records where not universally available which hindered some of the doctors.

I wasn’t even told that as a cancer patient I could get free prescriptions for 5 years. That was big news to me when I did found out several months into my treatment, especially as I was unable to work and on benefits.

My records did not include a simple chronological checklist of key dates and tests/procedures/results for doctors to refer to (in the end I made up my own spreadsheet which was a huge help)

I did get some great medical treatment, but I feel a lot of NHS money and time was wasted during the process (especially in prescription and appointment errors).

Often I wasn’t well enough to remember what I was told by the doctors — particularly instructions about what drugs to take and when. I used to get handed a big bag of stuff

I often had to remember to remind the doctor what prescriptions I needed ... it felt like a huge weight of responsibility.
APPENDIX 2
Written evidence from the Chartered Society of Physiotherapy (LTC 08)

The Chartered Society of Physiotherapy (CSP) welcomes the opportunity to provide evidence to the Health Select Committee inquiry into the Management of Long Term Conditions.

The Chartered Society of Physiotherapy (CSP) is the professional, educational and trade union body for the UK’s 51,000 qualified physiotherapists, physiotherapy students and support workers. 97% of qualified physiotherapists are CSP members.

Physiotherapy enables people with long term conditions (LTC) to move and function as independently as possible, maximising quality of life, physical and mental health and well-being and social participation. With a focus on quality and productivity, physiotherapy puts meeting patient and population needs, and optimising clinical outcomes and the patient experience, at the centre of all it does.

Physiotherapy has a key role to play in care for people with a range of LTCs including stroke; multiple sclerosis (MS) and other inflammatory diseases; Parkinson’s disease; chronic obstructive pulmonary disease; arthritis; musculoskeletal disorders; lymphoedema; asthma; mental health; chronic pain; and falls in the frail and elderly. CSP’s membership includes clinical specialists working with patients with these conditions and their carers. The evidence we submit draws on this expertise. We would be pleased to supply additional information on any of the points raised in our evidence at a later stage.

CSP Evidence

Summary of Key Points

— Significant and sustained resource reallocation is needed to ensure the community services necessary to reduce hospital admissions are available.
— Physiotherapy, as part of a multi-disciplinary care pathway, has been shown to be clinically and cost effective in treating patients with LTCs in the community.
— There is a risk that to make short-term savings community services are made less accessible and less effective, which stores up costs for the future and reduces patient outcomes.

1. The scope for varying the current mix of service responsibilities so that more people are treated outside of hospital and the consequence of such a service redesign for costs and effectiveness

1.1 There is significant scope for varying the current mix of services, requiring sustained resource reallocation towards community-based services, prevention, early intervention and reablement/rehabilitation. There is also scope to make better use of the skills and knowledge within the healthcare workforce. Physiotherapists have a detailed understanding of the physiological, social, physical and environmental causes of ill-health within people and populations and a high level clinical reasoning. Working across a variety of settings, they can co-ordinate and lead effective and integrated services for people with LTCs.

1.2 Northumbria Healthcare NHS Foundation Trust established an Early Supported Discharge team to support stroke survivors in the community. This multi-disciplinary team including physiotherapists has resulted in the average length of stay in hospital being reduced to half the national average and savings of around £500,000.

1.3 The HOPE Specialist Service at the North East Lincolnshire Care Trust provides a “one-stop-shop” for people with Chronic Obstructive Pulmonary Disease (COPD) and older people at risk of falling. The team includes physiotherapists, support worker specialists, volunteer “rehab buddies” and expert patients. Hospital admissions were reduced (1 per person attending the pulmonary rehabilitation course), and over four years, the falls and post hip fracture rehabilitation programme has seen an 8% reduction in visits to A&E and a 13% reduction in hospital admissions for people who have fallen.

1.4 Physiotherapy staff work in Rapid Response Teams and Emergency Departments. Wirral University Teaching Hospital have developed a service to support the A&E department by providing physiotherapy and occupational therapy assessment and reports and a range of practical follow-up services. The service has demonstrated significant reductions in bed days for the hospital.

2. The readiness of local NHS and social services to treat patients with LTCS (including multiple conditions) within the community

2.1 Physiotherapy, as part of a multi-disciplinary care pathway, has been shown to be clinically and cost effective in treating patients with a wide range of long term conditions in the community setting.

48 Physiotherapy works. Stroke. CSP January 2012
49 COPD is an umbrella term for a group of lung diseases that include chronic bronchitis, emphysema and small airways disease. Lung damage over a long period of time impairs the flow of air in and out of the lungs and causes breathlessness
50 Lung Improvement Case study. Hope for the Future—pulmonary rehabilitation. NHS Improvement, July 2012
2.2 COPD is the fifth biggest killer in the UK, and the second most common cause of emergency admissions in the UK. Pulmonary rehabilitation programmes are proven to reduce the length of hospital stay and readmissions.\textsuperscript{51} 52

2.3 Many musculoskeletal disorders (MSDs) are LTCs, and can be both a causal factor and caused by other LTCs. Early intervention with physiotherapy is clinically and cost effective. Self-referral to community physiotherapy has been demonstrated to save money and improve access.\textsuperscript{53}

2.4 The greatest potential for central nervous system adaptation and recovery occurs in the early stages of MS and early access to physiotherapy can reduce disability. Physiotherapy, as part of a specialist neurorehabilitative service, has a key role in managing specific symptoms of MS including pain, spasticity and the prevention of secondary complications. Results from clinical trials of MS exercise programmes have demonstrated benefits in muscle strength, cardiovascular fitness, aerobic thresholds and activity levels and functional ability.\textsuperscript{54} Over a six month period, a physiotherapy-led community service in Newcastle resulted in a decrease in GP and hospital consultant visits, the cost of the service was offset by a reduction in bed days.\textsuperscript{55}

2.5 Two out of every 1000 people in the UK suffer from lymphoedema. Early access to specialist physiotherapy-led intervention prevents the most disabling aspects of the condition associated with poor management. In the Abertawe Bro Morgannwg University Health Board in Wales, a lymphoedema team including specialist physiotherapists was established in 2004. This reduced cellulitis episodes for lymphoedema patients from 58\% to 9\%.\textsuperscript{56}

2.6 While there are many examples of excellent practice, there are insufficient community-based services for the treatment and management of LTCs, and a lack of integration between services in community and acute settings that can limit an individual’s recovery or rehabilitation.

2.7 Research conducted by the CSP and The Stroke Association in 2010 found that a quarter of stroke survivors had to wait longer than one month after discharge for physiotherapy.\textsuperscript{57}

2.8 In 2011 the CSP and the National Rheumatoid Arthritis Society (NRAS) published a report\textsuperscript{58} which revealed a third of patients not being referred for physiotherapy, a third waiting for more than one year, and just one in ten waited less than one month.

2.9 Short term savings through cuts in services and replacing experienced staff with staff on junior grades in community services for people with LTCs, risk additional and more costly needs for social care, medical interventions and longer hospital stays, as well as other financial costs to society.\textsuperscript{59}

3. The practical assistance offered to commissioners to support the design of services which promote community-based care and provide for the integration of health and social care in the management of long-term conditions

3.1 Physiotherapists and other allied health professionals (AHPs) have a unique insight and expertise working with patients and in multi-disciplinary teams across care settings in the management of LTCs, which should inform commissioning and service redesign.

4. The ability of the NHS and social care providers to treat multi-morbidities and the patient as a person rather than focussing on individual conditions

4.1 The impact of multi-morbidity is profound. People with several LTCs have markedly poorer quality of life, poorer clinical outcomes and longer hospital stays, and are the most costly group of patients that the NHS treats.\textsuperscript{60}

4.2 Physiotherapy takes a person-centred approach to care, taking into account the totality of an individual’s health and wellbeing needs, supporting self-management and informed choices. Physiotherapists address multiple and complex needs of patients through high-level clinical reasoning, diagnosis and treatment skills. Physiotherapists are accustomed to working in a variety of settings, across health and social care, and can be a valuable point of continuity and transition for patients moving from one setting to another.

4.3 The Proactive Care: Long Term Conditions pilot project started in April 2012 in the South Kent Coast CCG. Patients are supported by a multi-disciplinary team including a GP, community matron, health care assistant, physiotherapist, occupational therapist, pharmacist, health trainer, care manager and mental health

\textsuperscript{51} Physiotherapy works. Chronic Obstructive Pulmonary Disease. CSP January 2012
\textsuperscript{52} Pulmonary rehabilitation service for patients with COPD. NICE 2006 www.nice.org.uk/media/63F/4D/ PulmonaryRehabCommissioningGuide.pdf
\textsuperscript{53} Musculoskeletal Physiotherapy: Patient self-referral. Quality and Productivity Proven Case study (QIPP), NHS Evidence, NICE February 2012 (first published February 2011)
\textsuperscript{54} Physiotherapy works. Multiple Sclerosis CSP January 2012
\textsuperscript{55} Physiotherapy works. Multiple Sclerosis CSP January 2012
\textsuperscript{56} Physiotherapy works. Lymphoedema. CSP October 2012
\textsuperscript{57} Moving On. A vision for community based physiotherapy after stroke in England. The Stroke Association and CSP. March 2010
\textsuperscript{58} RA and Physiotherapy: a national survey. NRAS and CSP. October 2011
\textsuperscript{60} Managing people with long-term conditions. The King’s Fund 2010.
4.4 Physiotherapists in Brighton and Sussex Trust run exercise groups for people with LTCs, in an aquatic physiotherapy pool. Services are accessed through patient charities (National Ankylosing Spondylitis Society, Parkinson’s UK, Arthritis Care and the local Osteoporosis Society). This allows community-use of the facility when not being used and generates income.

5. Obesity as a contributory factor to conditions including diabetes, heart failure and coronary heart disease and how it might be addressed

5.1 Obesity is a contributing factor to a range of LTCs, including the physical stresses associated with obese bodies and their impact on patient’s neuromusculoskeletal and cardiorespiratory systems, movement, function and exercise-related risks.

5.2 Physiotherapists have a diverse skills set to identify strategies for the prevention and management of obesity, and the communication skills to build up trusting relationships required to address psychological and emotional barriers to taking up physical activity and accessing services.

5.3 The “Lose Weight Feel Great” service in Ashton, Leigh and Wigan PCT offers general health and wellbeing services as well as specialist weight management, that people can self refer to. One-to-one care is delivered by physiotherapist or dietician. Activate, the physiotherapy-led obesity service in Tower Hamlets has in its second year seen childhood obesity declining against a rising nation trend, despite local deprivation.

5.4 Physiotherapists support the management and prevention of obesity through prehabilitation of individuals awaiting surgery, and optimising post-operative recovery.

5.5 The emerging practice of specialist bariatric physiotherapy provides an understanding of the whole spectrum of available weight management interventions to support patients to access the most appropriate services for them. The CSP recommends the growth of bariatric physiotherapy, and for the routine inclusion of physiotherapists within weight management teams.

6. Current examples of effective integration of services across health, social care and other services which treat and manage long term conditions

6.1 Liverpool City Council runs an “Exercise for Health Scheme” at its leisure facilities. In 2008 the Musculoskeletal Therapy Team at the Royal Liverpool and Broadgreen Hospital started directly referring patients. Among other benefits, this led to a reduction in outpatient physiotherapy appointments for total knee replacements.

7. The implications of an ageing population for the prevalence and type of long term conditions, together with evidence about the extent to which existing services will have the capacity to meet future demand

7.1 Physiotherapy rehabilitation has a crucial role in keeping older people independent and restoring their independence, reducing the numbers of people requiring social care support or residential care, or delaying the need for such support.

7.2 Each year 35% of over 65’s, and around 45% of people over 80 fall in the community. Among the over 75’s injury from falls is the leading cause of mortality. Half of all people who have a fall will fall again in the next 12 months, increasing mortality, rates of hospitalisation and institutionalisation.

7.3 The physiotherapy-led Glasgow Falls Prevention Programme sees nearly 175 patients a month in their homes to assess risk factors and intervene to modify these. Between 1998 and 2008 admissions due to falls in the home reduced by 32%, falls in residential institutions by 27% and falls in the street by nearly 40%. Over the same period, the number of admissions for hip fractures decreased by 3.6% (compared with an increase of nearly 2% in England).

7.4 Investment in community physiotherapy services for older people is poor in many parts of England, and older people discharged from hospital and needing continuing rehabilitation, or those who have had a fall or a

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61 Kent Community Health NHS Trust, March 2013 The Human Touch, Transforming Community Services in Kent. Service in the spot light: Pro-Active Care: Long Term Conditions
62 Brighton and Sussex University Hospitals NHS Trust website http://www.bsuh.nhs.uk/departments/physiotherapy/specialist-areas/hydrotherapy/
64 LWFG website http://www.lwfg.co.uk/
66 ibid 
67 Physiotherapy works. Fragility fractures and falls. CSP January 2012
68 Physiotherapy works. Fragility fractures and falls. CSP January 2012
musculoskeletal injury at home, face long waiting times. This increases dependency on social services and the NHS.

8. The interaction between mental health conditions and long term physical health conditions

8.1 Four million people with long term physical conditions also have a mental health problems. For many people the experience of a LTC, including chronic pain, can result in anxiety, stress, depression and other mental health issues. There are psychological factors in behaviours around eating and exercise that can cause or exacerbate some LTCs.

8.2 Physiotherapists often work with psychologists on multidisciplinary teams for people with LTCs, and on mental health teams. As the “physical expert”, the physiotherapist has a key role in enabling physical activity for health promotion, disease prevention and relapse, and makes a significant contribution in the delivery of lifestyle, weight management and wellbeing programmes. They can act as care co-ordinator supporting service users to access services as and when needed. By utilising a rehabilitation and recovery model physiotherapists work with service users to develop and facilitate strategies for the journey through wellbeing and recovery.

8.3 As part of multi-professional teams, physiotherapists support care pathways and focus on the individual by: maximising service user independence; improving both physical and mental healthcare and the intrinsic link between the two; demonstrating flexibility in their role to improve person-centred care; working across sector and agency boundaries as part of integrated care pathways.

9. The extent to which patients are offered personalised services (including evidence of their contribution to better outcomes)

9.1 Physiotherapists are ideally placed to support the personalisation agenda, using their broad skills set to empower patients to take responsibility for their own health and achieve patient-centred outcomes.

9.2 Self-referral to physiotherapy is an excellent example of a personalised service which leads to better outcomes. NHS Evidence has included self-referral to physiotherapy for musculoskeletal conditions in QIPP.

9.3 Bristol Community Health’s Community Neurology Service aims to enable all patients with a long-term neurological condition to maintain independence at home. Working with NHS South of England and the Health Foundation they embedded the principals of patient centred care, shared decision making and patient self-management. Bristol Community Health now plans to introduce patient-held care plans for patients with long-term neurological conditions.

9.4 The Locomotor Service is a community physiotherapy service, which is part of Homerton University NHS Trust and manages 89% of musculoskeletal patients in the community. The Locomotor service has a chronic pain interdisciplinary service within it, allowing a smooth pathway from initial physiotherapy assessment to interdisciplinary management. The Locomotor sets goals with patients with chronic pain, to achieve personal function and quality of life goals. Patients are taught to manage persistent pain and flare-ups, and as a result visit A&E and their GPs with pain less frequently. Patients are also taught how to manage their medicines.

10. Services provided for people with diabetes

10.1 Physiotherapy not only helps to prevent type 2 diabetes, it can also have a profound effect on managing and treating diabetes and its associated complications.

10.2 Physiotherapists support patients to maintain good blood glucose control and achieve optimal body weight, through lifestyle advice and individualised exercise plans. Physical activity has been shown to improve glycaemic control to levels comparable to pharmaceutical intervention and should be a fundamental component of the interventions to manage type 2 diabetes.

10.3 Physiotherapists provide pain relief and help prevent and manage diabetic foot problems through advice, education and gait and posture training. Physiotherapists manage a range of musculoskeletal conditions commonly seen within the diabetic population, including shoulder adhesive capsulitis, which occurs in up to 30% of patients with diabetes.

10.4 Physiotherapy is an essential component of pre and post-amputation rehabilitation, supporting pre-operative assessment; decisions around amputation level; preparation for surgery; pain and wound management. It supports individuals to regain independence and social participation, through prosthetic rehabilitation and use of other adaptive equipment.

69 Long Term Conditions and Mental Health: The cost of comorbidities. The Kings Fund April 2012
71 Bristol Community Health website http://www.briscomhealth.org.uk/
72 Homerton NHS website http://www.homerton.nhs.uk/our-services/locomotor-services/
11. The definition of LTCs, and how this can provide more effective management of interventions necessary to bring about service change

11.1 Because chronic pain is not a singular disease entity or condition-specific, there is a tendency for this vital area to be ignored. Those living with chronic pain have higher incidence of poor mental health, poor sleep, poor physical mobility, obesity and related illnesses. They are also high consumers of health resources. We suggest cross referencing to the work of the National Pain Audit.73

7 May 2013

Written evidence from Nichola Ebbern (LTC 09)

SUPPORT FOR LYMPHOEDEMA

— Manual lymphatic drainage (MLD) is not a luxury and should be provided by the NHS as part of the health care package for sufferers.

— MLD practitioners should be registered and of an approved standard to ensure quality of care.

1. As a young sufferer of secondary lymphoedema following breast cancer, I would urge you to ensure manual lymphatic drainage (MLD) is provided as part of the standard care package.

2. I currently only receive compression garments from my local hospital and while these are vital to my care, they do not help my pain management or significantly ease my condition and improve my standard of living. I currently pay privately for MLD however to do this I have had to take out a loan. The financial implications of this are significant at a time when wages are not increasing while the cost of living is spiralling out of control.

3. Following advice from a fellow breast cancer sufferer, I contacted a MLD practitioner. There was little guidance regarding qualifications of the practitioner or the use of the various machines that help to break down the pooling of fluid in various parts of my arm. I was lucky in that my first enquiry resulted in a very competent and experienced practitioner; however there are many people who are not as fortunate. Like other professions, this should be a regulated profession with an easy follow system that allows people access to competent practitioners.

4. MLD relieves my pain and discomfort, allowing me to sleep at night and carry out many normal activities during the day. Without it my quality of life would be greatly reduced and I would be a bigger burden on the NHS as I would need sleeping tablets, pain relief medication and treatment for depression. All of these I had prior to discovering MLD.

5. This is a debilitating, life long condition and more care should be provided to sufferers. MLD should be provided to all sufferers in all healthcare trusts.

7 May 2013

Written evidence from the Lymphoedema Support Network (LTC 10)

SUMMARY

— Lymphoedema is a long term condition which current research and expert opinion supports, affects between 1.33 and 3.99 per 1,000 population. Prevalence increases significantly with age and based on these figures it is estimated that between 76,000 and 227,000 men, women and children in England are living with the condition. This would equate to an average of 400 to 1,000 per Clinical Commissioning Group.

— It is a common, chronic, disabling condition which has significant impact on patients’ quality of life.

— Current NHS and social care provision to stabilise and improve the condition and to support ongoing self-management is poor, with patients reporting difficulties in gaining a diagnosis, a lack of adequate provision to assess, treat and support self-management.

— Current lymphoedema services in England are demonstrably wholly inequitable with many services discriminating against those with non-cancer related lymphoedema and children who live with the condition.

— The incidence of the condition will increase with longer survivorship in cancer, an ageing population and increasing obesity rates as all are known to be contributory factors in the condition. There is currently poor strategic alignment between workforce planning, health care education and social services which is worsened by the current lack of NICE guidance, no agreed national tariff, no minimal education standards for lymphoedema practitioners, no agreed commissioning guidance and no National Strategy—it should be noted that all other home countries have, or are working on National Strategies for lymphoedema management.

73 http://www.nationalpainaudit.org/overview.html
— 36% of current services are managed by single handed practitioners and there has been a 2.37% reduction in the number of lymphoedema practitioners between 2009–11.

— Lack of timely, accurate diagnosis leads to increased complexity, increased costs and increased hospital stays as well as having a significant negative impact on the lives of those affected.

— It is estimated that for every £1 spent on lymphoedema treatments to limit swelling and prevent further damage and infection, the NHS saves £100 in reduced hospital admissions. Untreated lymphoedema costs the NHS more money in the longer term.

— Once treated and controlled lymphoedema can be self-managed with the right support both in terms of a good clinical and social services infra-structure. This may be as simple as a need for help to carry out skin care and put on compression garments—yet patients are told that this is not a community nurses job by the health teams and told it is a health problem by the social services teams—this lack of joined up care often sees patients’ condition return to levels at least as bad as they were before treatment and sometimes even worse.

1. What is Lymphoedema?

The lymphatic system is a network of vessels and nodes all over the body. Its main function is to transport lymph (a colourless fluid containing excess protein and immune cells) that forms naturally in the tissues. It also plays an important part in the body’s defence against infection. Lymphoedema is the name given to a swelling of the limbs, body or head that is chronic in nature (over three months), does not go down following elevation and does not respond to diuretics (water tablets). Lymphoedema is broadly divided into two types:

— **Primary lymphoedema**
  Usually develops as a result of a genetic fault with the lymphatic system. With under development or weakness of the lymph vessels, swelling can appear at or around birth or more often later in life such as at puberty. It can affect infants, children and men and women of any age and often runs in families.

— **Secondary lymphoedema**
  Develops when the lymphatic system is damaged. This may happen following treatment for cancer ie surgery or radiotherapy, but may also occur as a result of infection, traumatic injury, burns or when blood vessels are not working properly ie Deep Vein Thrombosis, varicose veins or leg ulcers. Patients who have reduced movement due to other causes are also at risk such as following a stroke, MS or paralysis.

2. How common is the problem?

It was once assumed that lymphoedema was mainly a problem associated with the treatment of cancers, particularly breast cancer and as a result most studies have focused on this. Studies in Wandsworth ([Moffat CJ, Franks PJ et al (2003) lymphoedema: an underestimated health problem. QJ Med; 92: 731–38](#)) and Derby ([Moffatt CJ, Pinnington L. (2012) HIEC Project Evaluation Report. Facilitating the development of community based lymphoedema services through clinical education](#)) found a prevalence of between 1.33 and 3.99 per 1,000 population respectively which rises steeply with age: 10.3 per 1,000 in those aged between 65 and 74 rising to 28.6 per 1000 in those over 85 years of age. It is therefore estimated that there are between 76,000 and 227,000 people in England living with lymphoedema. That equates to an average of 400 to 1000 individuals per CCG.

Three identified risks for lymphoedema are older age, having a cancer diagnosis and obesity—current projections suggest that all of these categories are expected to increase dramatically and as such the prevalence of lymphoedema will inevitably increase. With the current service provision already failing to meet current need this situation is a health and social care time bomb.

3. How is the condition managed?

3.1 Prevention

Whilst the primary form of lymphoedema cannot be prevented research suggests that in its secondary form, particularly in relation to breast cancer, quality patient information and early interventions can reduce the chance of developing lymphoedema or limit its consequences ([Torres Lacomba M et al (2010). Effectiveness of early physiotherapy to prevent lymphoedema after surgery for breast cancer; a randomised, single blinded, clinical trial. BMJ; 340; B5396](#)). This approach is reliant on both healthcare professionals and those at risk knowing about the condition and risk reduction factors. The LSN produces a wide range of patient information that is available via NHS Choices and the Information prescription initiative. Patients who are in contact with the LSN report that many GPs and community and hospital nurses have an alarming lack of knowledge about the condition and it is certainly true that the recognition, prevention and management of lymphoedema is not a priority in nursing, medical or physiotherapy training programmes. Last year the LSN commissioned a BMJ eLearning module on the subject aimed at GPs. In the first 12 months 2,141 UK doctors/physicians had completed the unit and whilst that is pleasing it is against a total number of GPs approaching 31,000 all of whom will be responsible for the long term condition support of lymphoedema patients.
Ev w22  Health Committee: Evidence

3.2 Treatment

Although lymphoedema is not currently a curable condition, treatments are available to reduce and control the associated swelling and skin changes and reduce the most common complications of cellulitis and leaking fluid (lymphorrhoea) (Ko DSC et al (1998) Effective treatment of lymphoedema of the extremities. Atch surgery; 133; 452–458). These treatments include:

— External compression—via multi-layer bandaging, intermittent pneumatic compression devices and, most commonly, compression garments.
— Skin care.
— Exercise and movement.
— Specialised massage—manual lymphatic drainage (MLD) or a self-administered version of this called simple lymphatic drainage (SLD).

3.3 Emerging technologies

No drug therapies have proven to be consistently effective for most types of lymphoedema. A number of important new technologies are being developed which will influence the future management of the condition—these include genetic, new methods of compression, surgical techniques such as lymph node transplants, liposuction and low level laser therapy.

4. Why should the NHS act?

4.1 Cellulitis

Due to the impact on the immune system that lymphoedema has, the most common complication of lymphoedema is cellulitis. This serious infection is a significant burden on the National Health Service. NHS Choices states that:

“In England in 2009, around 80,000 people were admitted to hospital as a result of cellulitis. The number of annual cases of cellulitis has increased three-fold over the past 15 years.” The cost of hospital admission for cellulitis in Derbyshire, Nottingham and Lincolnshire was approximately £4.1 million in one year against a population of Approx. 2.5 million. An average admission for cellulitis associated with lymphoedema in the previously mentioned Wandsworth study was 12 days and an estimated cost of £2,300.

4.2 Impact on the individual

Studies have demonstrated the significant impact lymphoedema has on the lives of those living with it (Todd J et al (2011) Service user research into social difficulties and appearance concerns in lymphoedema secondary to cancer. Macmillan Cancer Support) In the previously mentioned Wandsworth study the following data was found, which is backed up by the Todd study and direct patient feedback from the Lymphoedema Support Network.

— 80% of people with lymphoedema had to take time off work for treatment.
— 8% had to stop work completely because of their lymphoedema.
— 29% had experienced cellulitis in the previous year and 27% of these required hospital admission.
— 50% of patients suffered uncontrolled pain.
— 36% of people had received NO treatment for their condition.

A case study by the Lymphoedema Support Network Nurse Advisor graphically demonstrated these issues. A 63 year old gentleman developed lymphoedema as a complication of long term venous leg disease—for 18 months his case had been overseen by the community nursing team who had struggled to manage extensive ulceration. Lymphorrhrea and the emotional, physical and social burden of illness that the gentleman was living with. He was finally referred to a specialist lymphoedema service with the patient identified goals at commencement of treatment being “to stop smelly fluid leaking from my legs, to be able to play with my children again, to reduce my pain, to be able to get back to work and stop claiming benefits and to get my life back”. The cost of his medical treatment over these 18 months had been £20,560 and this did not include his benefits or other social costs. Following just nine sessions of treatment, at a total cost of £1,041 the gentleman’s legs were no longer leaking, his pain was significantly reduced, his swelling had reduced from the original 63% larger to just 5% larger, he had been reinstated to his job and was no longer claiming benefits, he said he had his life back!—he also required no visits from community nursing teams and was being supported in his on-going management by his GP.

4.3 Lack of appropriate initial assessment and treatment as well as a failure to support long term management is undoubtedly costing the NHS both in direct terms and in staff time and resources as well as causing many lymphoedema patients to be claiming benefits and needing significant social services input due to reduced mobility, pain and infection.
5. What could be done to improve the situation?

— Improved health and social care professional knowledge of the condition.
— The creation and adoption of a National Strategy for England for lymphoedema management.
— Improved access to Specialist care and on-going maintenance care for all living with lymphoedema regardless of cause, age or geography.
— NICE guidance on the management of lymphoedema/chronic oedema.
— The adoption of individualised joint health and social care care plans to assist with self-management of this long term condition.

7 May 2013

Written evidence from Prostate Cancer UK (LTC 12)

1. Overview

1.1 Prostate Cancer UK is the UK’s leading charity for men with prostate cancer and prostate problems. We support men and provide information, find answers through funding research and lead change to raise awareness and improve care. The charity is committed to ensuring the voice of people affected by prostate cancer is at the heart of all we do.

1.2 Prostate cancer is the most common form of cancer in men in England. Nearly 35,000 men are diagnosed with prostate cancer every year and 215,000 men are currently living with the disease. By 2030 it will be the most common cancer in the UK.

1.3 In the UK, one in eight men will get prostate cancer at some point in their lives. Older men, men with a family history of prostate cancer and men of black African and black Caribbean descent are more at risk.

2. Introduction

2.1 Prostate Cancer UK welcomes the opportunity to respond to the Health Select Committee’s inquiry on long term conditions.

2.2 Prostate cancer is a condition that men can live with for years. Men with localised prostate cancer (where it has not spread outside of the prostate) can have curative treatment but this can be associated with long term side effects. Men with advanced prostate cancer (where it has spread to other parts of the body) will also be living with the side effects of treatment. These side effects can include erectile dysfunction, loss of libido, fatigue, incontinence, depression and anxiety. They can appear either immediately after treatment, or sometime after and last for an indeterminate amount of time which can impact negatively on the quality of life.

2.3 The side effects from treatment for prostate cancer can be debilitating and last for several years. Whilst the side effects from surgery (prostatectomy) appear immediately, side effects from radiotherapy can take months and in some cases years to appear.

2.4 One and five year survival rates for prostate cancer are high. 93.5% of men survive for one year and 81.4% of men survive for five years.

2.5 Prostate cancer primarily affects older men. This means they are more likely to have other health conditions as well as prostate cancer.

2.6 After men have received radical treatment, their PSA (prostate specific antigen) level will need to be monitored yearly for the rest of their lives, as a surveillance measure in case cancer returns. Living with the potential for cancer to return can have a deep psychological impact.

2.7 Prostate Cancer UK have produced and published a Quality Checklist, which outlines the care men with prostate cancer can expect to receive from diagnosis through to end of life care. In the absence of a NICE Quality Standard for prostate cancer, it is essential that men are aware of their rights and how best to manage their care.

2.8 We have responded to a selection of the topics requested by the committee below, as relevant to support for men with prostate cancer.

3. The scope for varying the current mix of service responsibilities so that more people are treated outside hospital and the consequences of such service-redesign for costs and effectiveness

3.1 In respect to the most common forms of treatment for prostate cancer, surgery and radiotherapy, the recovery time is relatively short. Prostatectomies using robotic surgery, for example, can result in only a couple of days stay in hospital. However, the side effects can affect men for years after treatment.

74 For more information please visit our information pages at http://prostatecanceruk.org/information
75 The National Institute for Health and Care Excellence have delayed production of a Quality Standard for prostate cancer until 2014. Prostate cancer is the only common cancer not to have a published Quality Standard.
Ev w24  Health Committee: Evidence

3.2 In a survey we carried out 85% of men suffered side effects as a result of treatment. 76% of those men found the side effects difficult or very difficult to deal with.76

3.3 Presently, there are some services offered in the community, such as erectile dysfunction clinics, but these services are not available country wide. We believe that further scoping work should be undertaken to identify gaps in the provision of services, and are looking into what research we may be able to undertake. This should be targeted at side effects and how we can ensure that all men who need it have access.

4. The implications of an aging population for the prevalence and type of long term conditions, together with evidence about the extent to which existing services will have the capacity to meet future demand

4.1 Prostate cancer is a condition which primarily affects older men. As such, men with prostate cancer often have other health issues associated with old age. These can include arthritis, heart disease, hearing and sight problems and diabetes. Prostate Cancer UK believes there needs to be greater interaction between health and social care to address the fact that men are living longer and will therefore have greater needs.

4.2 This is why we have produced our Quality Checklist.77 We want to ensure that care is standardised across the whole of the UK and men receive appropriate care, regardless of where they live.

5. The extent to which patients are being offered personalised services (including evidence of their contribution to better outcomes)

5.1 Prostate Cancer UK believes there is more which can be done to ensure prostate cancer patients are offered personalised care. This should include regular check-ups by an appropriate healthcare professional, referral to specialist services if needed and a written care plan. Our own research tells that that whilst men value access to specialist nurses not all men are offered this vital resource.78

5.2 Data from the National Cancer Patient Experience survey shows that only 25% of prostate cancer patients were offered a written care plan.79 In order for care to be truly personalised, all men with prostate cancer need access to a specialist nurse and be offered a written care plan.

May 2013

Written evidence from the ME Association (LTC 13)

1. The ME Association

This is the submission from The ME Association (MEA). The MEA is a national charity that provides information and support for people who have ME (myalgic encephalomyelitis/encephalopathy) and chronic fatigue syndrome (CFS). It also funds research into the cause and management of ME/CFS through the MEA Ramsay Research Fund.

2. Summary

The key points being made in this submission relate to:

- Lack of sound epidemiological data on the prevalence of ME/CFS—which is needed to plan hospital-based services.
- Unacceptable delay in diagnosis and misdiagnosis—leading to poor management and poor prognosis.
- Lack of undergraduate and postgraduate medical education.
- Lack of hospital-based referral services in many parts of the UK resulting in a ‘postcode lottery’.
- Lack of hospital-based referral services for children and adolescents—even though ME/CFS is one of the commonest causes of long-term sickness absence from school.
- An almost complete absence of hospital-based services and domiciliary services for people with severe ME/CFS.
- A NICE guideline on ME/CFS which many people with ME/CFS, and their charity representatives, find unfit for purpose.

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77 For more information, please see http://prostatecanceruk.org/get-involved/campaigns/our-campaigns/quality-care-everywhere
78 Ibid
3. ME/CFS

3.1 Even though the clinical descriptions are different, ME is also known as chronic fatigue syndrome (CFS) and post-viral fatigue syndrome (PVFS). There is a great deal of confusion and debate over nomenclature and definition. For the purpose of this submission, we will refer to the commonly used composite term of ME/CFS.

3.2 ME/CFS is thought to affect at least 250,000 people in the UK. It affects all age groups, including children and adolescents where it has been identified as one of the commonest causes of long-term sickness absence from school. The most common age of onset is between 20 and 40 years of age in adults and 11 to 14 in children.

3.3 ME/CFS affects all social classes and ethnic groups.

3.4 ME/CFS is recognised to be a neurological disorder by the World Health Organisation (in section G 93.3 of ICD10)—a classification that is accepted by the Department of Health.

3.5 In the majority of cases the illness affects fit and healthy people who predate the onset of their illness to an acute viral infection, or some other immune system stressor, but then ‘fail to recover’.

3.6 The key symptoms include:
   — exercise-induced muscle fatigue and weakness;
   — post-exertional malaise/symptom exacerbation;
   — cognitive dysfunction involving memory, concentration, attention span, information processing;
   — orthostatic intolerance—difficulty with tasks that require standing;
   — pain—which can affect muscles, joints or nerves;
   — on-going infective or flu-like symptoms; and
   — sleep disturbances.

3.7 More serious neurological symptoms occur in a minority of people with ME/CFS, especially those at the severe end of the spectrum. These may include blackouts, atypical convulsions, loss of speech, loss of swallowing—which may require assisted feeding.

3.8 Reports into the illness—from the Chief Medical Officer (R1), Medical Research Council (R2), NICE (R3), Royal Medical Colleges (R4)—have all recognised the serious and persisting ill health and disability that is caused by ME/CFS along with an urgent need to provide hospital-based referral services and carry out research into both cause and management.

3.9 Around a quarter of all people with ME/CFS fall into the severely affected category—meaning they are housebound, wheelchair-bound or bed-bound at significant stages in the illness.

3.10 Research into prognosis indicates that while many people with ME/CFS stabilize only a small minority return to normal or near normal levels of health. Most people experience a significant degree of long-term ill health and disability.

3.11 The annual cost to the UK economy in relation to medical costs, benefit payments and lost revenue has been estimated to be around £3.5 billion (R5).

4. MANAGEMENT

4.1 We would like to bring to the attention of the Health Committee a number of concerns in relation to the management of ME/CFS. Some are shared with other long-term conditions whereas others are unique to ME/CFS.

4.2 These concerns are repeatedly raised by people with ME/CFS. They have also been raised on numerous occasions in both the House of Commons and the House of Lords, in meetings of the All Party Parliamentary Group on ME, which is Chaired by Annette Brooke MP, in adjournment debates, and in a joint charity forum (Forward ME Group) that is chaired by the Countess of Mar.

4.3 Unfortunately, very little progress has been made in addressing these concerns. And in relation to some aspects of management and NHS service provision the position has become worse.

4.4 The key points that we wish to make cover all points in the patient journey from diagnosis right through to management and support.

5. LACK OF EPIDEMIOLOGICAL DATA

5.1 Health service commissioners do not have meaningful epidemiological data on the prevalence and incidence of ME/CFS—information that is vital for commissioners in order to plan appropriate levels of service provision. Submissions from primary care trusts (PCTs) to the 2010 APPG report on NHS Service Provision (R6) confirmed that they do not have accurate patient numbers. There is therefore an urgent need for a comprehensive and accurate epidemiological study to ascertain the true extent of both diagnosed and undiagnosed ME/CFS.
6. Delay in Diagnosis

6.1 Many doctors lack the necessary knowledge and experience to confidently diagnose ME/CFS. Due to the historical background, some doctors still refuse to accept that ME/CFS exists as a clinical entity or are unwilling to use it as a diagnostic label. Consequently, a significant proportion of people with ME/CFS remain undiagnosed, misdiagnosed, or have to wait for an unacceptable period of time before the diagnosis is made.

6.2 A report by the ME Alliance (R7) found that:
   — 53% of people with ME/CFS waited for over a year for a diagnosis.
   — Only 25% were diagnosed within the six month period recommended in the CMO Report.
   — 45% of children and adolescents waited over a year for diagnosis, despite the recommended timeframe for diagnosis in this group to be three months.

6.3 As a result, people with ME/CFS often receive inappropriate or even harmful advice on management for a considerable period of time—which has a very negative impact on all aspects of management and the overall prognosis.

7. Lack of Medical Education

7.1 Much of the problem relating to diagnostic delay and bad initial management relates to the lack of medical education about ME/CFS at both an undergraduate and postgraduate level.

7.2 Organisations that are responsible for medical education—Medical Schools, Royal Colleges, General Medical Council—must therefore take a much more proactive role to ensure that all health professionals in training—doctors, nurses, occupational therapists, physiotherapists—see people with this illness and receive appropriate teaching on clinical assessment and management.

8. Heterogeneity of ME/CFS

8.1 ME/CFS is a heterogeneous condition—both from the point of view of clinical presentation and factors that are involved in causation and perpetuation. Consequently, any management programme must be linked to individual symptoms, severity of symptoms, and any other issues that may be involved in maintaining the illness—there is no place for an inflexible ‘one size fits all’ or an overly centralized approach.

9. Lack of Hospital-based Referral Services

9.1 There is currently a worrying lack of consistency in the way in which hospital-based referral services are organized for patients with ME/CFS, or where there is a possible diagnosis of ME/CFS. This was one of the main conclusions in the report on NHS Service Provision that was prepared by the APPG on ME. The report noted that:

   The APPG finds the degree of variation in the availability of and access to services unacceptable. Patient evidence also indicates people want services that are physician led, multidisciplinary, and are situated in locations that are accessible to those with significant mobility problems.

   The APPG recommend the DoH takes steps to remedy the variation and ensure that each PCT offers a range of services promptly—a process that should involve meaningful consultation with local patients or patient support groups.

10. Lack of Services for Children and Adolescents

10.1 In relation to children and adolescents the situation is even worse. This is largely due to the fact that most of the existing NHS referral services only provide diagnosis and management to people over the age of 16. The APPG report concluded:

   This is unacceptable and can lead to tragic consequences.

10.2 The APPG report went on to recommend that all involved should:

   Undertake a detailed review of current services for children and adolescents to ensure that all receive adequate care and that all decisions are made in conjunction with personal carers, education authorities and social services where appropriate.

10.3 Despite these very clear recommendations there has been no meaningful action from the vast majority of PCTs since 2010—and in some locations where specialist referral services have been set up these have later been downgraded or closed. This is clearly an unacceptable situation that must now be addressed by the new Clinical Commissioning Groups.

11. Lack of Services for People with Severe ME/CFS

11.1 As already noted, approximately 25% of people with ME/CFS will be classified as being severely affected at some stage in their illness.
However, this group have great difficulty in accessing hospital -based services, and are not normally offered any form of home—based domiciliary service. Dedicated in-patient beds for the assessment and management of people with severe ME/CFS are almost non-existent. Consequently, many people at the severe end of the spectrum receive no NHS care at all—a situation that is clearly inconsistent with the NICE guideline on ME/CFS.

11.2 The APPG report concluded:

"Specialist referral services must ensure that high priority is given to the needs of the severely affected, especially in relation to domiciliary services and in patient facilities for assessment and management."

12. THE NICE GUIDELINE ON ME/CFS

12.1 The current (2007) NICE guideline for the management of ME/CFS has been heavily criticized by people with ME/CFS, and the charities, on the grounds that it places far too much emphasis on the use of two behavioural interventions—graded exercise therapy (GET) and cognitive behaviour therapy (CBT)—that are consistently found to be either ineffective or even harmful by a significant proportion of people with ME/CFS. In addition, NICE has failed to recognize the fact that repeated surveys of patient opinion, including the one in the CMO report, have concluded that the most effective and safe form of activity management is a process known as pacing.

12.2 Surveys carried out by the ME/CFS support charities have repeatedly confirmed a high degree of dissatisfaction with the way in which the NHS is almost indiscriminately recommending these two treatments to people with mild or moderate ME/CFS.

12.3 The largest and most recently reported survey carried out by the MEA (R8), which involved over 4,000 respondents, found that in relation to CBT (997 respondents):

- 2.8% were ‘greatly improved’.
- 23.1% were ‘improved’.
- 54.6% were ‘no change’.
- 11.6% were ‘slightly worse’.
- 7.9% were ‘much worse’.

12.4 In relation to GET (906 respondents):

- 3.4% were ‘greatly improved’.
- 18.7% were ‘improved’.
- 21.4% were ‘no change’.
- 23.4% were ‘slightly worse’.
- 33.1% were ‘much worse’.

12.5 In relation to pacing (2137 respondents):

- 11.6% were ‘greatly improved’.
- 59.6% were ‘improved’.
- 24.1% were ‘no change’.
- 3.5% were ‘slightly worse’.
- 1.2% were ‘much worse’.

12.6 The NICE guideline also downgrades most aspects of the pragmatic management of key symptoms on the basis that there is an inadequate evidence based guidance of guideline production. This is not the position taken by the 2002 CMO Report into ME/CFS.

12.7 The MEA does not therefore believe that the NICE guideline is fit for purpose and we are very disappointed to learn that a proper review of this guideline with stakeholder input that was planned for 2013 appears to have been cancelled and will now replaced by some form of brief internal review.

13. SUMMARY

13.1 In summary, there are a number of issues relating to the management of ME/CFS that are not being addressed by all those who should be taking action. Most of these issues have already been referred to in reports to government—including the 2002 Chief Medical Officer’s Report and the 2010 report from the APPG on ME on NHS Service Provision. Sadly, there has been a distinct lack of action on behalf of all those responsible to address these concerns. This is clearly unacceptable.

13.2 Action therefore needs to be taken in the following areas:

13.3 An epidemiological study to establish the number of people—adults and children—with ME/CFS, along with the degree of severity. This will enable Clinical Commissioning Groups to plan an appropriate local level of service provision.
13.4 All health professionals should receive a proper period of medical education on the diagnosis and management of ME/CFS during their training. ME/CFS should also form part of continual professional development/education at a postgraduate level.

13.5 Early and accurate diagnosis in primary care, along with appropriate early management, to reduce the chance of a more severe and prolonged illness occurring

13.6 An end to the postcode lottery of NHS referral services—everyone with ME/CFS, adults and children, severely affected, should have access to a local hospital where physician-led specialist input on diagnosis and management can be obtained, where appropriate.

13.7 Physician-led multidisciplinary management programmes should be introduced which recognize that treatment has to be tailored to individual needs based on stage, severity and symptoms.

The ME Association would be very willing to give oral evidence to any of the hearings that the Health Committee intends to arrange on this very important topic.

8 May 2013

REFERENCES


2 MRC website section on research into ME/CFS: http://www.mrc.ac.uk/Ourresearch/ResearchInitiatives/CFSME/index.htm


5 Bibby J and Kershaw A. How much is ME/CFS costing the country: Report prepared by the Survey and Statistical Research Centre, Sheffield Hallam University for Action for ME 2003, and for Action for ME and The ME Association, 1996.

6 All Party Parliamentary Group on ME (March 2010). Inquiry into NHS service Provision for ME/CFS.

7 ME Alliance (2005). ME Diagnosis: Delay Harms Health. Early Diagnosis: why is it so important?

8 ME Association (2012). Managing my ME—What people with ME/CFS and their carers want from the UK’s health and social services.

Written evidence from Celesio UK and Lloydspharmacy (LTC 14)

1. INTRODUCTION

1.1 Celesio UK, which includes Lloydspharmacy, is one of the largest healthcare providers in the UK with a significant presence across secondary, primary and home care sectors. Each day Millions of people either use or rely upon the services which we provide.

1.2 We are a large and successful group which works in partnership with the NHS to help UK citizens live longer and healthier lives. Our corporate vision is a healthier world where more people can live life to the fullest.

1.3 In 2012, our 1500+ Lloydspharmacies dispensed around 150 Million prescriptions, 70+% of which related to medicines to treat those with long-term conditions. Other Celesio UK businesses also provide essential support and services to those with long-term conditions. Some examples include:

- Betterlife: which provides mobility aids and products to those with long-term conditions who require support of that nature to improve their quality of life.
- Evolution Homecare: which supports patients with certain chronic conditions to get treatment at home rather than in a hospital setting.
- Wilkinson's Healthcare: which—among other services—provides nurse-led care for stoma patients.

1.4 Therefore, from several different angles, but primarily from a community pharmacy perspective, Celesio UK has a broad and deep understanding of the needs of those with long-term conditions, the extent to which those needs are being met currently and where service improvements could be made.

1.5 The vast majority of those who suffer from long-term conditions will be on some form of medication and often multiple medicines for co-morbidity, particularly the elderly. As a result, community pharmacy
already plays an important and central role in supporting those with long-term conditions to understand and manage their medicines.

1.6 In England, this is achieved primarily through the New Medicine Service and Medicine User Reviews as well as ad-hoc advice and interventions by pharmacists and pharmacy staff when appropriate.

1.7 The New Medicine Service provides support for people with long-term conditions who have been newly prescribed a medicine to help improve medicines adherence. Medicine User Reviews (MURs) consists of accredited pharmacists undertaking structured adherence-centred reviews with patients on multiple medicines, particularly those receiving medicines for long term conditions.

1.8 As we will argue later these are important services, but not yet developed and embedded in commissioned care pathways as fully as they need to be.

1.9 Community pharmacy also plays a key role helping to identify those most at risk of developing long-term conditions. Community pharmacies provide frontline professional advice and information, refer individuals to their GP and many, including Lloydspharmacy, offer patient services/checks for conditions such as diabetes, high blood pressure etc.

1.10 On its own Lloydspharmacy has provided over 1.5 Million free Type 2 diabetes screening tests with 75,000 people referred to their GP and over 1.8 Million blood pressure tests have completed to date.

2. Community Pharmacy Future Project

2.1 The CEOs from Boots, Co-operative Pharmacy, Lloydspharmacy and Rowlands Pharmacy met with the Department of Health in October 2011 to discuss the future funding for community pharmacy. A “Community Pharmacy Future project” was initiated as a result with a vision of demonstrating the benefits pharmacy can offer, with an approach of reducing primary care admissions and delivering benefits for all parties. The project group looked at the delivery of services that address key objectives for Government’s three areas of focus including:

- Medicine optimisation.
- Public Health.
- Self care.

2.2 Two services were developed to demonstrate pharmacies ability to manage long term conditions. The services were developed and a pilot launched in September 2012 with the following services:

- A “COPD support and screening” service in the Wirral which recruited 308 patients.
- A “4 or More Medicine” service for patients over the age of 65; 627 patients were recruited to this service.

2.2 All local GP practices and relevant professional groups were engaged in the service including the PSNC, LMC, CCA and LPC. The service has been live for over 6 months and the initial results are extremely encouraging. The six month consultations for patients signed up to the service will all be completed by the end of June and the four companies will be able to share the detailed health economic data that will illustrate both the quantitative benefits of the pilot in addition to the qualitative benefits.

3. The Need for a New Approach

3.1 As a consequence of the growing number of those with long-term conditions, healthcare commissioners will need to review how services and support are delivered in the years ahead as current arrangements leave too many patients not accessing advice, getting available checks or taking their medicines as directed if at all. The consequences of this are an unacceptable high number of people dying prematurely, ending up in hospital requiring costly secondary care treatment—and often social care support—or becoming economically inactive (at a wider cost to the economy and benefits system).

3.2 There are several indicators that current approaches to identifying those most at risk of developing long-term conditions as well as providing ongoing professional support to those who do are not adequate:

- Large numbers of people with long-term conditions who may not be aware that is the case (e.g. around 850,000 people with undiagnosed type 2 diabetes).
- Large numbers of those with long-term conditions (between 30–50%) do not take their medication as directed if at all leading to premature deaths, avoidable hospital admissions and poorer quality of life.
- Avoidable deaths. For example, each year around 1,000+ asthma sufferers die prematurely because they are not using their inhaler properly (according to Asthma UK only 12% of asthma patients receive a written action plan from their GP or asthma nurse while one in five has not been invited for an annual asthma review).
- The number of diabetic patients who do not receive the regular check ups they require leading to avoidable amputations, strokes and heart attacks.
3.3 The essential problem is well known: the lack of a joined up approach to healthcare provision which leaves the patient to navigate their way through service silos.

3.4 We support fully the concept of patient-centric care pathways and joint professional working based around the needs of the patient. This is particularly important in the case of those with long-term conditions, many of whom require support from a range of healthcare professionals.

3.5 We want to see patient pathways in which GPs and community pharmacists share responsibility for providing continuing care through a joint care plan for those with long-term conditions.

3.6 An interesting example of this approach is being rolled out in Scotland. The Chronic Medication Service (CMS) is a national core service which all community pharmacies will eventually have to provide in order to be granted a community pharmacy contract. CMS requires GPs and community pharmacists to share responsibility for developing a care plan for patients with long-term conditions with much of the regular continuing care, support and health checks being undertaken by the pharmacist or pharmacy staff. It is not without its issues, but it is an example of how joined up care can be delivery.

3.7 There are other models and approaches worthy of consideration. For example, why don’t we see condition specialist nurses or even GPs undertaking outreach activity based in local community pharmacies working alongside the pharmacist or pharmacy staff to provide better support to those with conditions at high risk of developing avoidable complications? After all, the bricks and mortar, the consultation rooms as well as the professional expertise in medicines already exist. That would better utilise the community healthcare assets which are already in place.

4. So What Do We Need Going Forward?

4.1 There are a number of areas which need to be addressed if we want to improve the service and support given to those with long-term conditions and implement patient-centric care plans.

4.2 1. We need a new fit-for-purpose and appropriately funded community pharmacy contract based on patient services, not almost exclusively on volume dispensing.

4.3 That means a contract which provides the right kind of incentives to encourage partnership working with other healthcare professionals, particularly GPs. That in turn means the GP and community pharmacy contracts need to be aligned. The Chairman of NHS England has stated that he wants to review the GMS contract so now would be an appropriate time to consider alignment with the community pharmacy contract.

4.4 It also means clearly defining the role of community pharmacy—as CMS in Scotland is seeking to do—as a core requirement for managing those with long-term conditions, not an add-on extra.

4.5 Currently, not all community pharmacies provide the New Medication Service which means some patients do not automatically receive it. Similarly, the number of Medicine Use Reviews which a community pharmacy can carry out is capped at 400 per month: again this means some patients who would benefit from this service cannot access it. We believe both services should form a core part of an on-going healthcare plan for those with long-term conditions.

4.6 2. Patient care records

4.7 There needs to be a single patient record which both GPs and pharmacists can access.

4.8 3. Avoiding illness as well as treating conditions

4.9 It is preferable to stop people becoming patients. That will require a greater emphasis to promote healthy living and wellbeing. Community pharmacies are ideally placed to act as local community health hubs.

4.10 4. New models and service delivery

4.11 We need to see service commissioners considering new models to service delivery including online, tele-care and home based support. Companies like Celesio UK already operate across the primary, secondary and home care sectors and are therefore well placed to provide integrated healthcare services in partnership with commissioners.

5. Specific Questions

5.1 Q1. The scope for varying the current mix of service responsibilities so that people are treated outside hospital and the consequences of such service redesign for costs and effectiveness

— It is widely recognised that for clinical and financial outcomes it is better to treat people in community settings whenever possible. Part of the provision gap between GP (diagnosis) and hospital (treatment) is best met by community pharmacy. We should be looking at three pillars to our core NHS provision: GP, community pharmacy and secondary care.

5.2 Q2. The readiness of local NHS and social care services to treat patients with long-term conditions within the community

— Previous comments refer
5.3 Q3. The practical assistance offered to commissioners to support the design of services which promote community care and provide for the integration of health and social care in the management of long-term conditions

— We see a lead role for NHS England. We need local provision based on local needs but within national frameworks which avoid unnecessary bureaucracy (and cost), reinventing the wheel provision and postcode lottery provision.

5.4 Q4. The ability of the NHS and social care providers to treat multi-morbidities and the patient as a person rather than focusing on individual conditions

— Previous comments refer

— Currently we have a professional and condition focused approach. As most long-term conditions require medication (and many of those with long-term conditions have co-morbidity factors) there is a compelling case for community pharmacists to be involved at the core of designing and delivering patient care pathways.

5.5 Q5. Obesity as a contributory factor to conditions and how it might be addressed

— Previous comments refer.

— Greater use of community pharmacy as a local health hub as part of a wider approach to delivering improved public health outcomes.

5.6 Q6. Current examples of effective integration of services across health and social care

— Previous comments refer.

5.7 Q7. Implications of an ageing population

— Previous comments refer.

5.8 Q8. The interaction between mental health conditions and long-term health conditions

5.9 Q9. The extent to which patients are being offered personalised services

— Previous comments refer.

— Patients are still having to navigate their way around the healthcare system.

— Patients with long-term conditions will require the involvement of several healthcare professionals; we need to get better at describing from the outset who will support them in which ways for the rest of their lives.

8 May 2013

Written evidence from the Pemphigus Vulgaris Network (LTC 15)

The Committee is exploring the scope for more people with long-term conditions to be treated in the community and outside hospital. We quite understand the move towards treating more people in the community but think it is entirely inappropriate and potentially dangerous for those of us with rare and life-threatening dermatology conditions.

The Pemphigus Vulgaris Network wants to stress that treating us in the community and outside hospital is not what people with pemphigus vulgaris need.

Given that pemphigus is a volatile and life-threatening dermatology condition, we need our medical care to continue being treated in a hospital setting (ie following British Association of Dermatology guidelines).

Few GPs have ever had a pemphigus patient (it is an orphan disease) and whilst we need our GPs to be looking after our general health, especially given the possible side effects of necessary immuno-suppressives, the treatment for our condition needs to be determined by consultant dermatologists.

Indeed, if the pemphigus is not responding to standard drug regimens, this care may need (at various points) to be with consultant dermatologists who specialise in, and have a particular interest in, blistering diseases—as is being currently defined by the work of the NHS Specialised Commissioning Board.

To sum up: treatment in the community, outside a hospital setting, could put the lives of pemphigus vulgaris patients at risk.

8 May 2013
1. **Action Duchenne**

1.1 Action Duchenne welcomes the opportunity to respond to this consultation on living with a long-term condition.

1.2 We are a patient and parent run charity which raises awareness, funds research and campaigns for best standards of care for Duchenne (DMD) and Becker Muscular Dystrophy (BMD) throughout the UK.

1.3 Action Duchenne also keeps a registry of patients for research trials, hosts an education transition project and holds learning programmes produced for the specific requirements of people living with DMD and BMD.

1.4 Action Duchenne participates in the APPG for Muscular Dystrophy, holds round table meetings throughout the UK and provides advocacy support and information for members.

1.5 Action Duchenne would appreciate the opportunity to present evidence in person to the select committee.

2. **Duchenne and Becker Muscular Dystrophy**

2.1 DMD and BMD are rare, pervasive and complex conditions which affect every aspect of people’s lives and require constant monitoring and specialist care.

2.2 DMD and BMD affect ~1:3,600 male births and ~1:18,500 male births respectively.

2.3 The rapidly progressive nature of DMD, symptomatic from the age of around 4 or 5, leads to children being wheelchair bound by their early teens and increasing loss of upper limb function from their early 20s. BMD has a similar effect to DMD, however the progression is much slower, becoming symptomatic from early teens to late twenties.

2.4 The average life expectancy of those with DMD is their mid-20s, for BMD it is 50–60.

3. **Management of Duchenne and Becker Muscular Dystrophy and summary**

3.1 Due to the rarity of DMD and BMD and the complexity of the conditions’ effects “the best management of DMD requires a multidisciplinary approach with the input of specialists in many different areas” (Lancet Neurology 2010). The holistic, integrated and specialist approach required for best quality care for DMD and BMD has been accredited by NICE and underpins our response to this consultation.

3.2 The Service Specification for Neuromuscular services highlights how “the care of all patients should be led from a regional specialist centre with specialist Multi Disciplinary Team (MDT) providing regular local clinics”.

3.3 With the “best practice” DMD and BMD care, people can live much longer and experience a much greater quality of life.

3.4 **At the moment this is not happening.**

3.5 In Denmark, 50% of those living with DMD are over 20 years old, whilst, only 15% of those living with DMD in the UK are over 21. The population of DMD patients in Denmark has nearly doubled since 1990.

3.6 With coming research breakthroughs and improving standards of care, a greater number of exciting and ambitious young people living with DMD will need multidisciplinary specialist care and support. This must be planned for.
Specific Issues for the Consultation

4. The scope for varying the current mix of service responsibilities so that more people are treated outside hospital and the consequences of such service re-design for costs and effectiveness

4.1 The rarity of DMD and BMD means that all tiers of healthcare provided for patients must be directed by neuromuscular specialists. Action Duchenne is concerned that moving services out of specialist centres would reduce expertise and lead to a reduction in high standards of the multi-faceted and complex care required.

4.2 A great deal of our members experience poorly integrated care from professionals who do not have a full understanding of the condition both at hospitals and in local provision.

4.3 Our survey website, DMDCentres.org and our Boys to Men Campaign outlined the massive drop off of services for adults living with DMD, especially in primary care such as physiotherapy, but also with cardiac and lung monitoring.

4.4 Professor Hanna’s recent report on unplanned admissions for Neuromuscular conditions found that 37% of them were avoidable and concluded by recommending that monitoring of known neuromuscular patients and coordination of care across sub-specialties would reduce such unnecessary stress on patients and their families, as well as reducing costs.

4.5 At the moment, care is failing families and patients due to lack of understanding and expertise. This is also costing the health service more money.

4.6 As set out in the Service Specification for Neuromuscular Services, patients should be reviewed by a multidisciplinary team (comprising of neuromuscular consultants, a neuromuscular physiotherapist, a neuromuscular nurse, an occupational therapist, a speech and language therapist, a dietician, a psychologist and a neuromuscular care coordinator) every six months, with some patients who have rapidly progressing neuromuscular conditions (like DMD) being reviewed every three months.

4.7 The multidisciplinary team must also act as a hub, to facilitate access to colleagues including respiratory physicians, cardiologists, clinical geneticists, orthopaedic surgeons, endocrinologists, gastroenterologists, palliative care clinicians, occupational therapists and orthotists. There must be a procedure with which feedback
is given and processed to inform further care decisions. Indeed, if there are specific problems with a patient involving one of these specialists, that specialist should be involved in the multidisciplinary reviews. eg. The Standards of Care document states that from their early teens, people living with DMD should be seen at least twice a year for the monitoring of cardiac and lung function.

4.8 Multidisciplinary teams must ensure communication mechanisms exist between tiers 3, 2 and 1 so that local services such as physiotherapy, hydrotherapy, rehabilitation are well informed of patient’s requirements and the condition is monitored at a regular and local level.

4.9 A vital part of care from April 2013 for all those with DMD and BMD will be the assigned patient-held records, written and updated by the multidisciplinary team. Such records will act as a “passport” for proper care, allowing professionals who are not knowledgeable about the patients’ needs, to understand how to care for patients. Only with regular updates of these records will these be of use, and so Action Duchenne reiterates the need for regular MDT reviews of each patient.

4.10 Action Duchenne is concerned about the amount of care that will be commissioned by Clinical Commissioning Groups (CCGs) for rare conditions, and which care will be commissioned nationally by NHS England (NHSE) and the 10 Local Area Teams (LATs). If CCGs are not responsible for improving outcomes for people living with DMD and BMD, then CCGs may neglect important primary care services and the “postcode lottery syndrome” will prevail. It is also important to recognise that it is at primary level services such as physiotherapy where there are gaps. CCGs need direction from NHSE and LATs on provision of services for rare conditions.

5. The readiness of local NHS and social care services to treat patients with long-term conditions (including multiple conditions) within the community

5.1 People living with DMD and BMD often experience a lack of understanding of their conditions, which in turn leads to bad advice, a worsening of the condition and the “postcode lottery” syndrome of care.

5.2 From the recent Shire Report on Rare Disease Impact, (487 patients and 124 caregivers) 50% of patients with a rare disease and their caregivers stated they received conflicting information from different healthcare professionals about treatment options.

5.3 In the same study from Shire, 62% of patients and caregivers stated they needed to provide their healthcare professionals with information on their rare disease.

5.4 Diagnosis for DMD, on average, takes over a year from primary concerns being relayed to a GP. This highlights the GP’s problematic lack of expertise in DMD and BMD.

5.5 A recent study by the Muscular Dystrophy Campaign (600 patients and families) has shown that only two out five patients with Muscular Dystrophy felt that their GP understood their condition sufficiently to refer to them to the appropriate specialists, and more than half felt their GP’s limited knowledge of their condition mean they were unable to plan local care adequately.

5.6 The report by Shire, found that physicians (50) had limited resources and information to properly diagnose and manage rare diseases: 62% of these physicians felt that there weren’t the opportunities to network with other physicians who treat rare diseases.

5.7 As stated, people with DMD are now living much longer, but the health service has not kept up. This has led to a dearth of services for the adult population and many “dropping off” during transition.

5.8 Psycho-social care is absolutely vital, with families affected by DMD or BMD being at a higher risk of breakup and depression. People living with these conditions must have the option of specialist psycho-social care (not just advice from Care Advisors as set out in the Service Specification). Such care is often not available locally.

5.9 Breakthroughs in research may lead to expensive medicines coming to market. Action Duchenne is seeking assurance that a “postcode lottery” for the funding of new drugs will not arise. Moreover, such drugs will have to administered and monitored by experts, therefore once again highlighting the need for regional expertise.

6. The practical assistance offered to commissioners to support the design of services which promote community-based care and provide for the integration of health and social care in the management of long-term conditions

6.1 Action Duchenne is concerned that at a local level, the voices of patients and families living with DMD or BMD may be drowned out when it comes to community based care.

6.2 The Service Specification will act as a blueprint for specialised services, but each community will face individual issues. MDTs should work with CCGs to provide information about the holistic specialised care required.

6.3 The Service Specification must also change to take into account treatments coming to market and react to changes in standards of care eg the best use of steroids.
6.4 Healthwatch will also play a vital role in feeding back to LATs and NHSE in highlighting gaps in services. It is important to encourage families and patients living with rare conditions to involve themselves in these organisations and for the proper time and resources to be allocated to feedback on these conditions.

7. The ability of NHS and social care providers to treat multi-morbidities and the patient as a person rather than focusing on individual conditions

7.1 8% of adults living with DMD in the UK live at home compared to 20% in Europe. People living with DMD must be given care and support to fulfil their potential and be able to live independently if they wish.

7.2 DMD affects all muscles, causing problems throughout the body. Therefore all treatment must be multidisciplinary, holistic and treat patients depending upon their individual experience of the condition's progression.

7.3 The Specialist MDT will be able to respond to the progressive and complex nature of a patients' individual needs from a broader and holistic understanding in a timely and proactive way only if the links to local education, health and social care services are sufficient.

7.4 Current Specialist MDTs are under a great deal of strain, and clinical time for patients is very low. Only with a sufficient number of specialised clinicians and nurses will people and families living with DMD be given the time and information they need.

8. Obesity as a contributory factor to conditions including diabetes, heart failure and coronary heart disease and how it might be addressed

8.1 Obesity is a problem in DMD due to the lack of exercise and steroid use.

8.2 A specialist dietician must be a part of a Specialist MDT.

8.3 This dietician must link with the rest of the MDT, local services and provide specialist information depending on the steroid use of the patient and the individual circumstances.

9. Current examples of effective integration of services across health, social care and other services which treat and manage long-term conditions

9.1 Centres of Excellence such as GOSH and Newcastle already link local services together in a “hub-and-spoke model”.

9.2 Often patients and families cannot get coordinated and integrated care locally without a hub or care advisor organising their care. Families often have to re-explain the condition again and again to numerous clinicians.

9.3 Neuromuscular Care Advisors lie at the heart of integrating services across health, social care and other services. They must tie together the multitude of services required when living with DMD.

9.4 Given that DMD is symptomatic at a young age and the speed of progression of the disease requires education, health and social care to work together around the patient, Action Duchenne feels that those living with DMD must have Care Plans which include all of these aspects and MDT’s must have strong links to local education, health and social care services.

10. The implications of an ageing population for the prevalence and type of long term conditions, together with evidence about the extent to which existing services will have the capacity to meet future demand

10.1 The Duchenne population in Denmark has almost doubled since 1990, the average age has risen from 14 to 24 and people with DMD are now living into their late 40s. The number of people living with DMD will increase as standards of care improve and treatments come to market.

10.2 Existing services, especially in terms of specialist centres, are already under strain. These existing services must be planned long term, with the MDT in each region being formally developed to cope with the increase in population.

10.3 As drugs for DMD are developed, access to trials and monitoring of their efficacy can only be done by specialist MDTs. Therefore, it is vital MDTs in each region are set up swiftly, as set out in the service specification, and trials are accessible no matter where in the UK the patients live.

11. The interaction between mental health conditions and long-term physical health conditions

11.1 There is a much higher prevalence of SEN in those living with DMD.

11.2 Families break ups and depression are also much more likely in families living with DMD. Adequate psycho-social care must be provided from diagnosis for the patient and family, with proper information and follow up.
Ev w36  Health Committee: Evidence

11.3 Given the severity of the condition, the burden on families of organising adequate housing, transport and funding for appropriate carers on families is very large. Families must be supported and the progressive nature of the disease must be understood and planned for. Long term decisions must be made, with the families given a clear plan to lessen the possibility of depression and family issues.

11.4 Patient counselling should be available throughout school and into later life. Problems like bullying, depression and insular behaviour occurs in patients, whilst families and teachers often misinterpret the condition, leading to a lack of aspiration for the patient.

11.5 Action Duchenne anticipates that the new Education, Health and Care plans will be wanted by all parents. Inconsistencies in providing them could lead to anxiety among parents and representation will be needed for assessments.

RECOMMENDATIONS

1. The Service Specification must be adhered to in every region, with specialist MDTs in place as soon as possible.

2. MDTs must link with regional care providers, leading and linking up care.

3. MDTs must also be linked, via the care coordinator, with the education and psychosocial care of the patient and their family.

4. MDTs must be provided with long term funding and plans to ensure continuity.

5. The distinction between specialised care (commissioned nationally and led by LATs) and primary care (commissioned by CCGs) must be formalised to ensure the postcode lottery syndrome does not continue.

6. There must be a specific focus on ensuring the voices of patients and families living with rare diseases are heard at a local level through Healthwatch.

8 May 2013

REFERENCES


“Improving Lives, Optimising Resources: A Vision for the UK Rare Disease Strategy”, Rare Disease UK, 2011


“Becoming an adult: transition for young men with Duchenne Muscular Dystrophy”, Abbott and Carpenter, 2010


“Rare Disease Impact Report”, Shire, 2013

Written evidence from Centre for Mental Health (LTC 17)

ABOUT US

Centre for Mental Health is an independent national charity working to improve the life chances of people facing or living with mental ill health. We act as a bridge between the worlds of research, policy and service provision and we promote high-quality evidence and analysis. We encourage innovation and advocate for change in policy and practice through focused research, development and training. Our evidence to the Committee is derived from our research and analysis work. We have responded to the Committee’s questions on which we have relevant knowledge.
EVIDENCE

The scope for varying the current mix of service responsibilities so that more people are treated outside hospital and the consequences of such service re-design for costs and effectiveness.

The readiness of local NHS and social care services to treat patients with long-term conditions (including multiple conditions) within the community.

The practical assistance offered to commissioners to support the design of services which promote community-based care and provide for the integration of health and social care in the management of long-term conditions.

The ability of NHS and social care providers to treat multi-morbidities and the patient as a person rather than focusing on individual conditions.

At least one-third of people with a long-term physical illness in England also have a mental health condition, most commonly depression or anxiety. People with a severe or enduring mental illness, meanwhile, typically have very poor physical health. In neither case is the NHS currently well placed to offer “whole person” care to people living with a combination of mental and physical ill health. The barriers to integrated care include:

- Different payment systems: The development of Payment by Results in mental health care has been slow and there is not yet a national tariff in place. Differences in the way mental and physical healthcare are paid for have hampered the development of integrated support.
- Diagnostic overshadowing: People with a long-term physical illness rarely have their mental health needs recognised. Likewise, people with a severe mental illness seldom receive adequate support for their physical health despite having very high rates of smoking, obesity and alcohol dependency.
- Poor outcome measures: the NHS, public health and adult social care outcome frameworks contain few measures relating to multi-morbidity. Data collection tends to focus on single conditions and episodes of care, obscuring the needs of people with multiple conditions.

Current examples of effective integration of services across health, social care and other services which treat and manage long-term conditions.

Community mental health services have for a long time featured high levels of integration between health and social care. Social workers are embedded in community mental health services, including teams with specialist functions such as crisis resolution, early intervention and assertive outreach. A growing minority of mental health services also integrate support with housing, employment, welfare and debt advice.

There is increasing evidence of the economic benefits of integration: the Individual Placement and Support approach can help more than half of people using mental health services into paid work, compared with a national employment rate of about one in ten, yet it costs no more than traditional vocational services. One of its key components is the integration of health and care, employment support and benefits advice.

The implications of an ageing population for the prevalence and type of long-term conditions, together with evidence about the extent to which existing services will have the capacity to meet future demand.

The interaction between mental health conditions and long-term physical health conditions.

Mental and physical health are inextricable. People with a mental health condition are more likely also to have a significant physical illness and to experience poorer outcomes.

Depression is at least twice as common among people with a range of long-term conditions including stroke, COPD, cardiac disease and diabetes. Cardiovascular patients with depression have higher mortality rates: including a 3.5 times higher death rate following a heart attack. People with diabetes also have higher mortality rates and a greater risk of complications if they also have depression.

The cost to the NHS of mental ill health among people with a long-term physical condition is an estimated £10 billion. This additional cost can result from poorer self-care, higher rates of hospitalisation and outpatient service use, and greater use of medications. Improving mental health support for this group could significantly cut the extra costs and generate large savings to the overall health economy of an area (including to social care). Measures that would help to reduce the cost and improve quality of care include:

Liaison psychiatry services in general hospitals: these offer immediate access to mental health support throughout the hospital. They provide specialist treatment as well as advice and training to other hospital staff. The biggest cost savings can be achieved through reduced admissions and lengths

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80 Naylor C, Parsonage M and Fossey M 2012, Long-term conditions and mental health. London: The King’s Fund and Centre for Mental Health

81 Centre for Mental Health 2009 Commissioning what works. London: Centre for Mental Health

82 Summarised in Naylor C, Parsonage M and Fossey M 2012, Long-term conditions and mental health. London: The King’s Fund and Centre for Mental Health

83 Naylor C, Parsonage M and Fossey M 2012, Long-term conditions and mental health. London: The King’s Fund and Centre for Mental Health
of stay among older patients, particularly those with dementia. A well-managed liaison psychiatry service could cut the costs of a “typical” hospital by £5 million a year.\textsuperscript{84}

Improving access to psychological therapies: the IAPT programme is beginning a pilot programme to extend psychological therapy access to people with long-term conditions and those with medically unexplained symptoms.

Collaborative care: there is growing evidence that integrated health support for people with co-morbid physical and mental health conditions is cost-effective.\textsuperscript{85} This is achieved through appointing a “care manager” who coordinates all the services an individual requires and offers advice and support for self-management.

For people with a severe mental illness, better physical health support is vital to close the 15–20 year life expectancy gap. This should include tailored smoking cessation services, medication management and practical support with diet and exercise. Emerging evidence from the United States suggests that multi-disciplinary teams working to support the physical and mental health (as well as social care, housing and financial needs) of people with a severe mental illness are cost-effective.\textsuperscript{86}

The extent to which patients are being offered personalised services (including evidence of their contribution to better outcomes)

Mental health services are increasingly moving away from their traditional focus on symptom management to a new focus on helping people to achieve personal recovery. Taking a recovery approach means focusing on what people need to achieve the best possible life with or without the symptoms of mental illness. Clinical care remains important but it is in support of other goals in life (eg relating to work, family and friends) and it is the individual service user who determines their own priorities.

Key features of recovery-oriented mental health services include increased use of Peer Support Workers—people whose experience of mental illness enables them to offer hope and knowledge to others—and the development of Recovery Colleges, which provide education opportunities and are delivered by service users, carers and professionals together.\textsuperscript{87} The use of personal budgets can also support a recovery focused service. A pilot in Northamptonshire offering personal budgets to mental health service users found that about two-thirds of the money was spent on “traditional” mental health care while the remaining one-third was spent on a range of alternatives including personal assistants, exercise, education and IT equipment.\textsuperscript{88}

Evidence about the outcomes that recovery-focused services can achieve is still emerging. Longer term evaluations of Recovery Colleges and Peer Support Workers are yet to be attempted. Nonetheless, we do know that supporting people with mental health conditions into paid employment generates significant improvements in physical and mental health, including evidence of reduced hospital admissions over time.\textsuperscript{89}

9 May 2013

Written evidence from YoungMinds (LTC 18)

S U M M A R Y

— Many children and young people could be defined as having a long-term mental health problem, but many more are likely to have more transitory mental health difficulties.

— About half of all adult mental health problems start in childhood. So whilst long-term management for mental health problems is important, it is essential that there is also effective early intervention provision.

— People with mental health problems often have multiple morbidities, and we know that they often struggle to access adequate mental health support.

— Only a quarter of young people with a mental disorder are in contact with specialist mental health services. Barriers to young people accessing services need to be addressed in order to prevent their mental health problems becoming chronic and enduring.

— A number of areas are developing home treatments or alternatives to inpatient provision. These include examples from the voluntary sector.

\textsuperscript{84} Parsonage M and Fossey M 2012, Liaison Psychiatry in the Modern NHS. London: Centre for Mental Health and NHS Confederation


\textsuperscript{87} Perkins R and Repper J 2012, Recovery Colleges. London: Centre for Mental Health and NHS Confederation

\textsuperscript{88} Alakeson V and Perkins R 2012, Recovery, personalisation and personal budgets. London: Centre for Mental Health and NHS Confederation

\textsuperscript{89} Centre for Mental Health 2009 Commissioning what works. London: Centre for Mental Health
Integrated working in relation to child and adolescent mental health services (CAMHS) is generally poor. Health and Wellbeing Boards are in a good position to bring together relevant agencies and ensure that children and young people’s mental health needs are reflected in their JSNAs and Joint Health and Wellbeing Strategies.

The transition between CAMHS to adult mental health services is a perennial problem that still needs to be adequately addressed. Providing effective mental health and wellbeing support at what can be a very vulnerable point in a person’s life will reduce the number of young people developing long-term mental health problems.

1. YoungMinds is the UK’s leading charity committed to improving the emotional well being and mental health of children and young people by ensuring these issues are placed firmly on the public and political agenda. We achieve this through the provision of research, lobbying, influencing policy and campaigning. Driven by the experiences of children, young people, parents and carers we also raise awareness and provide expert knowledge through training, outreach work, and publications.

2. We are pleased to see the inclusion of mental health in the brief for this Inquiry. Many mental health problems in children and young people are ongoing and fit the definition of long-term conditions as defined by the Department of Health. This is important because in the UK one in 10, or nearly 850,000 children and young people aged between 5–16 years have a mental disorder.\(^9\) The prevalence will be even higher in some vulnerable groups. For instance, 36% of children and young people with learning disabilities will have a mental health problem.\(^1\) Many more children and young people will experience mental health difficulties, but will not meet the clinical threshold and so will not be defined as having a mental disorder, but are likely to be very distressed.

3. About half of all adults with mental health problems were first diagnosed in childhood. Therefore, effective interventions during childhood and adolescence can help prevent mental health difficulties becoming chronic and enduring illnesses. So whilst it is essential to provide effective support for long term conditions, effective early intervention should not be forgotten.

**Multiple Morbidities**

4. Many people with mental health problems have more than one mental health problem, or they may have a drugs problem, or a learning disability. Having multiple-morbidities can have a great impact on the treatment received. NICE guidance, which provides evidence based advice on how to manage conditions, generally focus on a single condition. This means that there may not be guidance to help staff manage cases where people have more than one condition. Anecdotally we know that some services will not treat people with mental health problems if they also have a drug problem. We know that 71% of children with autism also have a mental disorder, and that many of them will not be able to access child and adolescent mental health services (CAMHS) (National Autistic Society, 2010).\(^2\) So the long-term management of young people with multiple morbidities is fraught with difficulties and may result in some young people not accessing adequate mental health support.

**Concern about Young People not Accessing Mental Health Services**

5. We are concerned about the large number of young people who do not access mental health services, despite having a mental disorder. Research has found that over three quarters of young people with a mental disorder were not in contact with specialist mental health services, and just over two fifths were not in contact with any service.\(^3\) These young people would benefit from specialist mental health services, but it is likely that many will not access mental health services until their problems become quite serious. Not receiving timely and effective treatment is likely to result in their mental health problems becoming chronic and enduring.

5.1 Young people are put off accessing services for a variety of reasons, but the chief reason is the stigma associated with mental health.\(^4\) Other reasons include long waiting lists, difficult referral systems, not being taken seriously etc.\(^5\) Young people have reported in numerous consultations that they want holistic services that meet their mental health needs, but also provide access to a range of help and support; and they want the opportunity to take part in activities that are fun and creative, and help them build a range of softer skills such as building


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friendships. This range of services, especially the opportunity to develop the softer skills is especially important for young people with long-term mental health problems as their illness can significantly impact on their school and personal life.

5.2 It is important that young people have easy access to services that are flexible and tailored to individual needs eg not “9 to 5” or “wait until Monday” and they want to be seen in the environment that works best for them—this may be at home, or in the clinic, but it may also be in a coffee shop. They want services to use the web, mobiles, text, email to improve communication and services should outreach into schools and other agencies.

5.3 Involving young people in decisions about what services should look like and how they should operate will help engage them with their own care and improve the quality of long-term health care.

Home Treatment

6. We know of several services that offer home treatments or alternatives to inpatient provision. For instance, Sussex Partnership NHS Foundation Trust, have invested in community approaches which have reduced the need for outpatient placements, and they have reduced the average length of inpatient stay for young people from 40 to 20 days. Savings made have been reinvested in innovations such as the Urgent Help team, which has reduced the need for inpatient admissions and length of stay.

6.1 In South Wales, there is the Community Intensive Therapy Team (CITT), which is aimed at young people who need more support than that usually provided in outpatient settings. This service reduced the need to admit young people to inpatient units, and between 2001–06 there were no referrals to Tier 4 services (inpatient services and other high specialist provision) outside of the region. http://www.bmj.com/rapid-response/2011/10/31/community-intensive-therapy-team

6.2 Many young people prefer to access voluntary sector services as they are often on the high street and are less stigmatising. For instance, Youth, Information, Advice and Counselling Services (YIACS) offer a range of different services under one roof. Research has found that the young people accessing these services have very high levels of mental illness (Youth Access, 2012). YIACS have different configurations including counselling services, sexual health, drugs advice etc, but The Zone in Plymouth—offers a range of services including access to an early intervention psychosis service, and a service for young people with emerging personality disorders.

Integrated Services

7. From our consultancy work, we know that there is a history of silo working in CAMHS and that local agencies do not always work together to provide truly integrated services. The current economic situation is not helping. Our work on cuts to CAMHS services has found that 34 out of 51 (Two-third’s) local authorities in England have reduced their CAMHS budget since 2010. These cuts to local authority CAMHS budgets are very likely to impact on the ability of local agencies to work together.

7.1 There are many reasons why local agencies have difficulties with integrated working. For instance, different agencies often use different terminology and this can hinder integrated working. There needs to be a shared understanding of mental health and wellbeing, and of the range of services that are required, and what the responsibilities are for each agency.

7.2 Relevant services in a given area need to work in genuine partnership to plan, commission and deliver the full range of mental health services including those for long-term conditions. The different agencies need to have a mandate and incentives to encourage them to work in partnership. There also needs to be good leadership within these agencies to drive forward partnership working. Partnership working relies on trust, and this needs to be nurtured and developed through good working relationships between staff in different agencies.

7.3 Health and Wellbeing Boards are in a good position to improve integrated working. In order for these new bodies to achieve this, they must have representation from voluntary sector providers.


organisations, the justice system, and education, as well as the members stipulated in the Health and Social Care Act 2012. This will enable a wide range of agencies to come together and feed in to their local joint strategic needs assessment (JSNA) and their joint health and wellbeing strategy.

7.4 Health and Wellbeing Boards must ensure that their JSNAs take account of the mental health needs of children and young people. This needs analysis data must be reflected in their joint health and wellbeing strategies and ultimately in the local commissioning plans of the clinical commissioning groups (CCGs) and the local authority.

TRANSITIONS

8. Transitions between CAMHS and adult mental health services AMHS are a perennial issue, and there have been many attempts to address it. CAMHS generally only see young people up until their 18th birthday, and then if they need ongoing access to services they will have to move to adult mental health services. This transition point is generally seen as a weak spot in service provision. The Track study has highlighted how it can be difficult for young people to make the transition from CAMHS to AMHS. For instance, it found that although young people were referred to AMHS, many were not accepted because they were not “ill enough” and did not meet their acceptance criteria. Also, some young people would not engage with AMHS and so disengaged with services. The Track study (Singh, 2010, cited in Joint Commissioning Panel for Mental Health, 2012), which focused on these transitions, found that “a third of teenagers are lost from care during transition and a further third experience an interruption in their care”.

8.1 Problems associated with this transition can result in vulnerable young adults being left with no support at a critical point in their lives, when they most need help. In particular, there is particular a lack of continuity of care and service provision for young adults with Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorders (ASD) and personality disorders (ref Singh). All of these conditions are long-term conditions, often with negative outcomes. For instance, the consequences of not providing adequate support can result in people not accessing help until they come into contact with the justice system.

CONCLUSION

9. Children and young people will need to have long-term care for their mental health problems, but there is also a need for them to have access to mental health services when their problems first emerge. This is important as access to effective early intervention services will reduce the chances of their problems becoming more chronic and enduring, and is more cost effective.

9.1 Many people with mental health problems have multiple morbidities, but we know that most will not receive a holistic service that addresses the full range of their needs. Therefore, long-term care needs to be more holistic to address these people’s needs.

9.2 Mental health services for young people need to be accessible and they need to have a choice about where they are seen, whether that is at home, a cafe, or other appropriate locations. This is because clinics can be stigmatising and put young people off accessing help when they need it.

9.3 Transitions between CAMHS and AMHS is a perennial problem, and not addressing this problem can result in young people dropping out of services until their problems become more chronic and enduring.

10 May 2013

SUMMARY

— The main causes of sight loss in the UK are long term conditions: age-related macular degeneration, diabetic retinopathy and glaucoma. Reducing preventable sight loss from these conditions is an objective in the Public health outcomes framework.

— Our ageing population and the introduction of new treatments mean that demand for services to treat these eye conditions is increasing.

— Services’ ability to diagnose and treat people quickly and effectively varies across the country meaning that people in some areas are probably losing their sight to preventable causes.


1. Long term eye conditions: rising numbers and the impact of sight loss

1.1 Three long term conditions are responsible for most cases of sight loss in the UK: age-related macular degeneration (AMD), diabetic retinopathy and glaucoma.

1.2 **AMD** is the biggest cause of sight loss in the UK. A recent study estimated that 2.4% of people in the UK aged 50 years or more had advanced wet AMD, increasing to 4.8% of those aged 65 years or more and 12.2% of those aged 80 years or more.\(^{105}\) Smokers are three times more likely to suffer AMD.\(^{106}\)

1.3 The following table shows how the number of people with advanced AMD is predicted to rise by a third to 679,000 this decade (the middle line shows prevalence amongst women and the bottom line prevalence amongst men):

![Late AMD](image)

1.4 **Diabetic retinopathy** is the biggest cause of sight loss amongst people of working age in the UK. It occurs when diabetes weakens the blood vessels in the eye. People with diabetes are 25 times more likely than the general population to become blind.\(^{107}\) Diabetes UK estimates that by 2025 there will be five million people in England with diabetes\(^{108}\) and for each year someone lives with diabetes, their risk of retinopathy increases.

1.5 **Glaucoma** is estimated to affect about half a million people in England. The prevalence of glaucoma rises steeply with advancing age. African-Caribbean people are at particular risk. More than half of those glaucoma cases are thought to be undetected\(^{109}\)

1.6 The Government is committed to reducing preventable sight loss from these three long term conditions through an indicator in its *Public health outcomes framework*. We strongly support this.

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1.7 Sight loss has a major impact on people’s well being. Sight is the sense people most fear losing. Over one-third of older people with sight loss are also living with depression.\textsuperscript{110} Two-thirds of registered blind and partially sighted people of working age are not in paid employment.\textsuperscript{111}

1.8 People with a long term eye condition often have other health problems too. Sight loss is associated with a heightened risk of falls and fractures\textsuperscript{112} and people with a long term eye condition often have other long term conditions, such as dementia and diabetes.

2. The capacity of existing services to meet future demand

2.1 There is emerging evidence that eye care services are unable to meet current demand and will not meet rising demand in the future without significant improvements.

2.2 A recent survey found that half of all hospital eye units in England were unable to treat AMD patients within the recommended waiting times that would minimise their risk of sight loss.\textsuperscript{113}

2.3 Professor Sir Bruce Keogh’s evidence to the Health Select Committee in January that cataract surgery was being rationed inappropriately by half of PCTs highlighted the strain hospital eye units are under as they struggle to meet existing demand, much of which is fuelled by long term conditions.

2.4 Our recent report, Better data, better care showed how the NHS’ reliance on paper forms for payment and referrals hindered care and wasted valuable time and resources in the fight to prevent sight loss from long term eye conditions.\textsuperscript{114} The failure to enable community and secondary care teams to share data is a major drag on the capacity of existing eye care services to meet demand now and in the future.

3. Taking advantage of community optometrists to redesign services, meet demand and integrate care around patients’ needs

3.1 There are examples of innovation, which if properly implemented across the NHS, would boost our capacity to meet the needs of people with long term eye conditions in the future.

3.2 Taking glaucoma care, for example, NICE recommends that patients at risk of glaucoma be monitored in the community by optometrists through “repeat measures” schemes rather than in hospitals. More advanced monitoring in the community (referral refinement) is also recommended by the College of Optometrists and the Royal College of Ophthalmologists.\textsuperscript{115} Together, these schemes improve glaucoma patients’ access to quality care by increasing the capacity of their eye services. They keep less serious cases out of hospitals and take advantage of thousands of community optometrists already performing sight tests and caring for patients in the NHS. They can also save significant amounts of money; NHS Evidence found that moving repeat measurement for glaucoma in to the community in Bexley was 62% cheaper than the equivalent hospital tariff.\textsuperscript{116}

3.3 To minimise sight loss from AMD, Gloucestershire has introduced a one stop shop model with integrated IT. Rather than assessing and treating patients over two visits, here assessment and treatment clinics run in parallel using non-consultant staff in particular nurse practitioners and optometrists. All clinical data is recorded electronically, allowing the consultant to make rapid treatment decisions for new and returning wet AMD patients using information on patient electronic medical records.\textsuperscript{117}

3.4 In most of England, we do not know the answer to simple questions like, how many patients are we treating for glaucoma or if at risk groups get their eyes examined. Scotland has been particularly innovative in overcoming IT barriers by integrating the electronic systems of community optometrists and hospitals eye unit to improve access to better quality care and improve efficiency at the same time. Following a successful pilot, the Scottish Government is committed to ensuring that 95% of referrals from community optometrists to hospitals are done electronically rather than in paper. Paper referrals are the norm in most of England. Moving to electronic referral means community and hospital clinicians can share much more information about their patients over time with the aim of improving the continuity of care, reducing unnecessary referrals to the hospitals, improving efficiency and improving patient outcomes.


3.5 Scotland is also working towards making provider payment forms electronic. Electronic payment facilitates much better data collection about who is accessing eye care and how to design services that improve the care of populations with long term eye conditions. However, in England, most optometrists must submit their payment forms, which include potentially valuable public health data, in paper form making it extremely difficult to analyse the data to improve eye health services.

3.6 If accomplished, the Government's push for a paperless NHS offers great potential to improve eye care for people with long term conditions.

3.7 The move to involve clinicians more closely in commissioning also offers potential to improve care. NHS England is introducing Local Eye Health Networks to each local team area to bring together commissioners, community and hospital clinicians and patient groups to work together to assess local need and improve the quality and efficiency of eye health services for their local population. We strongly recommend that commissioners take advantage of these networks and are supporting our members so they can contribute fully.

8 May 2013

Written evidence from reMEember (The Chronic Fatigue Society) (LTC 20)

Summary

— Services in the community are not yet prepared or organised to receive patients who hitherto would have been treated in hospital.
— At the same time CCGs are required to make cost savings which limits scope for improvement.
— ME/CFS patients make little demand on hospitals, but services in the community for them are deficient in many areas. A national review of provision and implementation of reforms could save money in the long run.
— Voluntary organisations are ready and willing to help commissioners of services.
— Education is usually the answer to problems like obesity.
— There is some integration across health/social care and other services but much more needs to be done. Welfare benefits are seen by many long term patients as their biggest problem.
— An ageing population will cause increasing demand for health and social care services.
— There is a need for closer integration between mental and physical health services. Treatment of the “whole person” is vital, and voluntary organisations can play a key role here.

Submission

1. Scope for treating more people outside hospital. The length of hospital stays has been dropping for many years because of advances in surgery and medicine generally. However, taking people with long term conditions out of hospitals and treating them in the community requires very sophisticated infrastructures which are not yet in place. reMEember, along with other voluntary organisations such as the British Heart Foundation, Diabetes UK and Age UK, are working with a Clinical Commissioning Group in Sussex to identify local needs and how they may be met in the community. A key point here though is that the CCGs are required to make considerable cost savings over the next few years so the scope for necessary improvements may be limited.

2. reMEember’s area of concern is the long term condition ME (myalgic encephalomyelitis) also known as Chronic Fatigue Syndrome. Very few people with this illness are treated in hospital (some would probably benefit from respite care but this tends not to happen). The treatment and care provided in the community is patchy and of varying standards. Some places still have no ME/CFS service. Children can be particularly badly affected by this illness but there are few services for them. There is little or no domiciliary provision for those who are too ill to attend an out-patient clinic. Some of the services have no doctor attached to them, and where there is one it is usually a GP with a special interest (GPWSI). This is not good enough; in a significant number of cases patients diagnosed as having ME have been subsequently diagnosed with another condition (eg cancer). Therefore consultants are needed. A particular problem is the lack of statistics relating to sufferers; no audit has ever been carried out. As to treatment, patients may receive a course of Cognitive Behavioural Therapy or similar for a limited period but after that they are just referred back to their GPs and there is no provision for review at a later date. reMEember performs an important role by providing self management classes and keeping in regular contact with sufferers. There ought to be a national review of ME/CFS provision looking critically at the shortcomings of the present system and recommending major improvements. This would be very cost-effective in the long run. It is well recognised that early, accurate diagnosis and intervention leads to better outcomes.

3. Readiness of local NHS and Social Care services, and practical assistance offered to commissioners. As noted in paragraph 1 above, the community services are not yet prepared (having only recently been formed), and we fear they may not be ready for a long time because of the extensive work needed and limited resources. Voluntary organisations like reMEember are very willing to offer help and expertise, but trying to fulfil this requirement is going to involve a very hard struggle.
4. Treating multi-morbidity and “the person not the condition”. We recognise the importance of this. ME/CFS can vary tremendously in its severity and there are often co-morbidities which are not picked up because the symptoms are thought to be “part of the ME”. There is scope for education of health care professionals here. reMEmber’s approach is to help patients identify their goals and action plans and find ways of achieving them using techniques such as stress management, problem solving, pacing, meditation, effective communication skills, and diet/healthy eating.

5. Obesity. We recognise this is a particular problem in conditions like diabetes and heart disease, but interestingly enough it is hardly ever found in ME patients. Mostly they lose weight, some of them drastically. In those conditions where obesity occurs the answer is nearly always education.

6. Examples of integration across health/social care and other services. We understand this is already happening in some areas. There is a need for providers of all services to get together with commissioners to address this subject. Integration should include the subject of state benefits such as employment support allowance (ESA) and personal independence payment (PIP). A large number of ME sufferers report benefits as their biggest problem, particularly the attitude of agencies such as Atos. Patients fear being declared fit for work when they are not with a consequent devastating loss of income. In Sussex reMEmber is working with the team set up by the CCG to enhance and improve integration.

7. Implications of an ageing population. There is no doubt that the numbers suffering from dementia, arthritis and other conditions associated with old age will increase, making things very tricky for commissioners and providers of services. There is no evidence that the number of ME/CFS sufferers increases with old age, but often there is misdiagnosis—for example the fatigue commonly experienced by elderly patients is mainly not ME/CFS, but may be diagnosed as such. Diagnosis by consultants can be the answer to such problems.

8. Interaction between mental health conditions and long term physical health conditions. For many conditions a clear distinction is not appropriate. A number of physical conditions produce a serious deterioration in mental health too. Also people who have been ill for a long time are quite likely to suffer from less striking mental health conditions such as depression or anxiety. This is unsurprising given that they may have lost their jobs, income, friends etc. A research study in 2012 found that children with ME/CFS suffered anxiety not as a result of their physical illness but because of being away from school, isolation, attitudes of family and friends etc. If we are to treat the “whole person” successfully, interaction between mental health experts and the other practitioners is necessary.

9. The extent to which patients are being offered personalised services. We understand this is happening in some areas, but these initiatives appear to be “one offs”. Machinery is needed to ensure that all appropriate services are brought together for each patient. Voluntary organisations can play a key part in this, as many already perform a co-ordinating role with the various services.

8 May 2013

Written evidence from The Nottingham Traumatic Brain Injury Service (LTC 21)

SUMMARY

— We wish to share with you our experiences of supporting people with the complex issues that result from a Traumatic Brain Injury as we believe that this model can successfully be implemented with other long term conditions.

— The Nottingham Traumatic Brain Injury Service is an example of multi-professional expertise treating and promoting self-management of patients with this complex long term condition.

— It is a specialist case management lead service for people with moderate and severe brain injury with additional input from a specialist Cognitive Behavioural Therapist, a specialist Occupational Therapist and an experienced Assistant Practitioner.

— The team provide support and treatment to the patient and their families from their post injury in-patient stay through into the community.

— The aims of treatment are to help patients maximise their level of function, adapt to and self-manage any residual problems and where possible return to previous roles including work and education.

— This highly personalised service requires the team to work with agencies across the all sectors including primary and secondary healthcare including mental health services, social care, education providers, DWP, justice system, third sector, employers and recently the armed forces for veterans transitioning to civilian life.

— Patient and family/carer feedback consistently demonstrates a very high level of satisfaction with the service, clinical outcomes demonstrate effectiveness and recent research has indicated a higher quality of life and return to work rate for patients receiving this specialist care as opposed to usual care.
1. The Nottingham Traumatic Brain Injury Service began life as a research project hosted by Warwick University to evaluate the effectiveness of different models of delivery of brain injury rehabilitation. It was jointly funded by health and social care and moved away from the medical model by being a case manager lead service. The case managers have come from a variety of professional backgrounds including nursing, social work and occupational therapy. They provide therapeutic interventions, education and support and guide the patient and their family through the rehabilitation process, accessing other services as required. The team also has an Occupational Therapist, a Cognitive Behavioural Therapist (CBT) and an Assistant Practitioner. Funding for the CBT post came to support the team with those patients who were developing difficult to manage behavioural issues that were requiring high cost, specialist residential placement. It was argued and we have now shown that early intervention can prevent behavioural problems developing, the team has not needed to recommend or use such a placement for the last 4 years.

2. Our model utilises the specialist skills of the team and also supports the patient in accessing a wide variety of health, social, education, employment and voluntary services. Liaison and joint working are the norm, recent examples include working with social care, including child protection services, community based neurological therapy services, the police and probation service, housing associations, higher and further education providers, DEA and DWP, the Armed Forces Personnel Recovery Units, mental health services including drug and alcohol teams and third sector providers of voluntary work placements.

This model is an efficient use of the specialists’ time and ensures that patients access the other services they require at the most appropriate point in their rehabilitation pathway. This reduces waste and duplication, improves effectiveness and aligns with the right care, right place, right time ethos.

3. The case manager model provides continuity and personalised care for the patient and their family. Early intervention is often targeted at the family to support them in the early phase of recovery after the patient is discharged from hospital. Good education and appropriate support of family members can decrease the length of hospital stay and reduce the amount of support services required.

Interventions are delivered at a time and place to suit the patient and their families. This is often at home but can be a variety of community settings, including libraries, education settings, leisure facilities and the work place as required. Treatment programmes are individualised based on a comprehensive assessment and goals are agreed with the patient. Interventions continue as long as there are agreed, achievable rehabilitation goals and the focus is always self-management.

Feedback is sought via questionnaire from patients and their families after six months with the service and after discharge. The information is used to guide service developments.

4. The services vocational rehabilitation outcomes have been formally assessed. A recent College of Occupational Therapists funded Phd study demonstrated that compared to those receiving usual care, those being treated by the specialist service had a higher return to work rate, they reported a higher quality of life and had a reduced length of hospital stay. Those people who had returned to work also reported statistically significantly less depression and reduced anxiety levels compared to those people not in work. The economic evaluation showed similar costs across the pathways with the specialist service costing a mere £75 more than usual care. (Reference—Return to Work after Traumatic Brain Injury—Cohort comparison and economic evaluation. Brain Injury, May 2013;27(5): 507–520. On line link—http://informahealthcare.com/doi/abs/10.3109/02699052.2013.766929)

5. As more people survive Traumatic Brain Injury due to improved medical interventions, the prevalence of TBI is increasing in the population. Once the person has survived the initial injury, TBI does not limit life expectancy. Given that the average age of the 94 patients in the study quoted above was 34 years, people are living for many years with the effects of their brain injury. Evidence shows that early intervention can maximise recovery, promote return to work and minimise the dependency on health and social care services with the associated societal costs.

CONCLUSION

The experience of the Nottingham Traumatic Brain Injury Service over 21 years demonstrates that a specialist multi professional team working to the case management model is an cost efficient and clinically effective method of providing support and rehabilitation to patients with complex physical, cognitive, psychological and social needs.

We believe that this model is applicable to other groups of patients with complex long term conditions and we would be happy to share our more of our skills, knowledge and experience with the select committee or other interested parties.

8 May 2013
Written evidence from Dwayne Johnson (LTC 22)

As the Strategic Director, Communities with statutory responsibilities for adult social care in Halton Borough Council I do feel it is appropriate and relevant that the end of life care services are not forgotten within the context of managing long term conditions. It is often very difficult for our health clinicians to provide an accurate prognosis of life expectancy. We will be informed that an individual has only a short period of life, when on many occasions individuals survive long after their prognosis. There are an increasing number of people surviving longer because of improved health and social care services. This means care services are managing a long-term condition whereby their life expectancy was determined to be short. In addition it is important to recognise that many people who have a long term condition are nearing the end of their life. I therefore believe that the Committee should be cognisant of these matters and feel this of relevance to the Inquiry. I have provided below a couple of examples to highlight this to the Committee.

The practical assistance offered to commissioners to support the design of services which promote community-based care and provide for the integration of health and social care in the management of long-term conditions

The numbers of people dying in hospital has continued to rise whilst a number of surveys indicate that, given a choice, a large majority of people would choose to be cared for at home. Recent research by the Nuffield Trust reaffirmed the inter-relation of health and social care at the end of life, and the need to provide a holistic approach focused around the individual and their needs and wishes. Social services have access to and make best use of local intelligence (health and social care data sets) to focus on the design and delivery of end of life care improvements in all sectors. Engagement with the emerging clinical consortia, commissioning support organisations, and health providers across acute and primary care settings, local hospices and local authorities is well developed to ensure the effective pooling of resources to facilitate the commissioning and design of new services, with a clear understanding of the shared service improvement agenda.

Current examples of effective integration of services across health, social care and other services which treat and manage long-term conditions

Best practice in end of life care within local authority services includes working with a wide range of stakeholders such as hospices local colleges, social care providers including care homes, extra care schemes, domiciliary providers and supported living establishments. These networks have allowed commissioners to develop innovative approaches and interventions to support a range of service user groups. The recent publication of the National End of Life programme Sharing successful strategies for implementing supporting people to live and die well highlights good practice across England demonstrates how effective integration can be to support people with long term conditions and in particular those people nearing the end of their life.

8 May 2013

Written evidence from the Joint Epilepsy Council (LTC 23)

The Joint Epilepsy Council (JEC)

JEC is an umbrella charity which provides the representative voice for people affected by epilepsy.

JEC works for a society where people with epilepsy receive the best possible care and support; represent the united voice of epilepsy in the UK and present evidence based views on the need for improved epilepsy services and influence decision makers in the health, social and education arenas.

Epilepsy is a neurological condition which presents in as many as 50 different types. It is diagnosed when someone has recurrent seizures (also known to many people as fits). It is caused by excess electrical activity in the brain.

More than 600,000 people are known to have epilepsy in the UK. It is the most serious neurological condition and is a major long-term disability with similar numbers of people affected as insulin dependent diabetes.

The Management of Patients with Epilepsy

Almost one in 100 people have epilepsy. 600,000 are prescribed epilepsy medication. Over 1,000 people a year die from epilepsy—60% of child deaths and 40% of adult deaths from epilepsy are avoidable.

At least £268 million a year could be saved if the NHS were simply to stop misdiagnosing patients. If further steps were taken to improve the management of this long term condition then additional millions could be saved.

In recent years the Prime Minister, Department for Health Ministers and officials, All Party Parliamentary Groups, NICE, the Right Care Project, the National Specialised Commissioning Group and numerous other organisations and individuals have all accepted that the management of epilepsy as a long term condition in the UK has failed for many years and continues to do so.
Ev w48  Health Committee: Evidence

It is therefore immensely frustrating that despite these acknowledgements and a superficial willingness to act, the NHS continues to provide a woefully inadequate service to the vast majority of patients with epilepsy in the UK. We very much hope that the Health Select Committee inquiry into the management of long term conditions will recommend some concrete actions to significantly improve the health care provision for those with epilepsy.

RESPONSE

JEC is pleased that the Select Committee wishes to consider the extent to which existing services will have the capacity to meet future demand but would like to highlight the fact that current demand is not being met and this must be addressed as a matter of urgency before contemplating the long term future.

75 people a day are diagnosed with epilepsy and the number is growing. Epilepsy mortality rates are rising and they compare unfavourably to many other European countries.

In the UK there are 1.6 deaths per 100,000 compared to 0.5 deaths in Spain, 0.7 in Italy and Portugal, 0.8 in Austria, 0.9 in Sweden and 1.0 in the Netherlands. Other countries such as Denmark, Finland, Belgium and France similarly have standardised death rates below that of the UK.

INTERACTION BETWEEN MENTAL HEALTH CONDITIONS AND LONG TERM PHYSICAL HEALTH CONDITIONS

20–30% of those with learning disabilities have epilepsy. Children with epilepsy often do not realise their full educational potential with 30,000 children estimated to be under achieving academically in relation to their intellectual capabilities.

Seizures result in missed lessons but they also cause short and long term memory problems and difficulties with concentrations and information retention. Similarly even for those children who take medication that controls their seizures, the side effects of such medication can affect memory and attention and lead to underachievement. This can only be overcome where there is an individual assessment, otherwise it is impossible to know how best to support a child with epilepsy.

It is striking that there is not a single reference to epilepsy in the department for Education’s “Special Educational Needs Code of Practice.” Epilepsy is not currently defined by the DfE as a condition that may give rise to Special Education Needs despite the fact it obviously does so.

THE EXTENT TO WHICH PATIENTS ARE BEING OFFERED PERSONALISED SERVICES

Put simply patients with epilepsy are not being offered personalised services.

NICE guidelines published in 2004 state that anyone with a suspected seizure should be referred to an epilepsy specialist within two weeks. 90% of trusts fail to do this. There is absolutely no punishment for trusts failing in this area and equally there is no real incentive for them to do so. These guidelines have been consistently disregarded by the vast majority of trusts for almost a decade. Therefore it does not seem unreasonable for a radical overhaul to take place.

A further demonstration of the woeful lack of personalisation in epilepsy care is demonstrated by the fact that only 14% of patients have a care plan despite this being classed as a key indicator of the National Service framework for long term conditions (2005) and a key element of the repeatedly ignored NICE guidelines (2004 & 2012).

Many trusts do not employ a single neurologist who specialises in epilepsy and more than half do not have a single epilepsy specialist nurse. It is therefore hardly surprising that a personalised service is not being offered to the hundreds of thousands of patients who have epilepsy.

A lack of personalisation also means that over £20 million per annum is wasted on misdiagnosis with a staggering 100,000+ people unnecessarily taking epilepsy medication.

50% of epilepsy sufferers make a full contribution to society because their condition is controlled. An additional 20% could join them in doing so with a more personalised service.

8 May 2013
Written evidence from MSD-UK Ltd (LTC 24)

At MSD-UK, we believe the most important thing we make is a difference.

We operate in more than 140 countries and through our prescription medicines, vaccines, biologic therapies, and consumer care and animal health products we work with customers to bring innovative healthcare solutions to those who need them the most. We also demonstrate our commitment to increasing access to healthcare through far-reaching policies, programmes and partnerships.

MSD is a trade name of Merck & Co., Inc., with headquarters in Whitehouse Station, N.J., U.S.A. MSD has been based in the UK for more than 80 years:

— We are a significant provider to the NHS.
— We invest many millions of pounds in our UK facilities, including our laboratories in Hoddesdon which are a world-wide centre of excellence in chemistry.
— The UK is also home to one of MSD’s most important manufacturing facilities outside of the US, producing tablets for worldwide markets.
— We have the largest veterinary production facility in the UK.
— We employ more than 2,000 people across four UK sites.

Executive Summary

— Despite improvement in the last decade, more can be done to manage long-term conditions in the UK, for example UK lags behind European counterparts in improving CVD mortality rates.
— Inequalities and variation in long-term condition mortality rates & access to care remain across the UK.
— Proactively addressing long-term condition risk factors more robustly in the community-setting, such as for Cardiovascular Disease and Type 2 diabetes, has the potential to deliver a more “effective” NHS service (eg EiP Greenwich case-study). This should be driven through measures that encourage quality and can deliver overall cost-efficiency in the NHS, rather than short-term cost-savings with potential unintended consequences.
— It is critical that we align how we measure and incentivise health-care professionals (& NHS England bodies) with national clinical guidelines on long-term condition risk factor management in order to address mortality rates, quality of life and costly complications.
— Quality measures need to go beyond “testing” alone to ensure long-term conditions and risk factors are being effectively addressed nationwide and to further narrow inequalities.
— With the creation of NHS England and the removal of certain information & education structures (eg NHS diabetes) it is key that new support structures are adopted rapidly in order to offer practical assistance to commissioners.
— There are a number of examples of effective integration of services across health, social care and other services which treat and manage long-term conditions (eg First Diabetes (Derbyshire), EiP Greenwich case-study).
— With an increasing ageing population it is key that more is done to address disease management of long-term conditions in the community-setting in order to improve mortality rates, quality of life and prevent costly hospital admissions and care. This should be supported by appropriate measurement and outcome indicators that are focussed on long-term savings not solely short-term savings.

We welcome the Health Select Committee’s inquiry into the Management of Long-Term Conditions. The points we would like to raise are as follows:

1. Despite improvement in the last decade, more can be done to manage long-term conditions in the UK, for example UK lags behind European counterparts in improving CVD mortality rates

1.1 Although significant improvements in the prevention and treatment of CVD over the last decade have been made, CVD remains one of the largest causes of death and disability in the UK.  

1.2 The Global Burden of Disease Study demonstrates that UK could do better in improving CVD mortality rates in comparison with other European countries.

1.3 It is estimated that that there are approximately 2.5 million people diagnosed with Type 2 diabetes and up to 850,000 undiagnosed in the UK.

1.4 The recent DUK State of the Nation report highlights that only half of people with Type 2 diabetes get the annual tests and investigations that are recommended in the national standards. Importantly, even where

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testing is taking place, many patients are not achieving the recommended target range for risk factors. More must be done to address this.\textsuperscript{121}

2. Inequalities and variation in mortality rates & access to care remain across the UK

2.1 A wide variation in the treatment and management of diabetes across England remains.\textsuperscript{122}

2.2 There are geographical inequalities across the UK in CHD mortality and this is often worse in areas of highest deprivation.\textsuperscript{123}

2.3 Another example of a national health inequality exists in the diagnosis and management of Familial Hypercholesterolaemia (FH) or “inherited high cholesterol” across the devolved nations.\textsuperscript{124}

2.4 The recent NHS Information Centre on the “Use of NICE appraised medicines in the NHS in England 2010 and 2011, Experimental Statistics” showed that there was a variation in utilisation of medicines for long-term conditions. For example, the ratio of observed to expected usage of a NICE-approved non-statin cholesterol management therapy in the London SHA was approximately 0.6 in 2010 and 0.55 in 2011 versus nearly 0.9 in 2010 and nearly 0.8 in 2011 in the South East Coast SHA.\textsuperscript{125}

2.5 Access restrictions to NICE approved medicines remains a problem at local formulary level, which can lead to postcode prescribing which reinforces healthcare inequalities.\textsuperscript{126}

3. Proactively addressing long-term condition risk factors more robustly in the community-setting, such as for Cardiovascular Disease and Type 2 diabetes, has the potential to deliver a more “effective” NHS service. This should be driven through measures that encourage quality and can deliver overall cost-efficiency in the NHS, rather than short-term cost-savings with potential unintended consequences

3.1 NHS spending on diabetes was almost £10 billion in 2011, which was 10% of the NHS budget. 80% of NHS spending on diabetes goes into managing avoidable complications. People with diabetes account for around 19% of hospital inpatients at any one time, and have a three day longer stay on average than people without diabetes. Most of type 2 diabetes costs are due to hospitalisation.\textsuperscript{121}

3.2 More effective risk factor management in the community has the potential to reduce costs to the NHS, while improving quality of care.

3.2.1 Evidence into Practice (EiP) is a clinical change management programme. The programme aims to ensure that people with diabetes and those at increased cardio-metabolic risk receive optimal care through the effective implementation of national policy and guidelines, particularly NICE Type 2 Diabetes Guidelines. An example of the success of this approach was demonstrated in Greenwich. Results after one year showed that in practices who took up the programme a significant improvement in patients achieving NICE-recommended risk factor targets were achieved and substantial overall cost-savings were demonstrated due to a reduction in hospital admission rates. NICE have endorsed EiP as a proven case study for QIPP. NICE concluded that the programme scored 100% for evidence of change and 75% for both savings made and quality. This approach enabled the delivery of higher standards of care at a lower overall cost to the NHS.\textsuperscript{127}

3.3 However, current national QIPP standards often focus on short-term drug budget savings through prescribing indicators rather than encouraging optimising medicines in line with NICE quality standards, guidelines and recommendations.

3.3.1 For example, although the NICE Type 2 Diabetes guideline (CG87)\textsuperscript{129} outlines a number of treatment pathways based on individual patient profile utilising older and newer therapies appropriately, the QIPP prescribing comparator for diabetes is solely based on the use of low cost drugs relative to newer therapies.

3.3.2 Medicine optimisation is about ensuring the right patients get the right choice of medicine at the right time and how patients comply. National measure of quality such as QIPP prescribing comparators and other outcome indicators should be focussed around NICE quality standards

\textsuperscript{122} www.rightcare.nhs.uk/index.php/atlas/diabetes (last accessed 9 May 2013)
\textsuperscript{123} www.heartuk.org.uk/latest-news/article/cholesterol-and-a-healthier-nation (last accessed 9 May 2013)
\textsuperscript{124} Saving Lives, Saving Families. The health, social and economic advantages of detecting and treating familial hypercholesterolaemia. HEART UK.
\textsuperscript{126} http://www.hscic.gov.uk/media/1354/QIPP-Prescribing-Comparators-Description_and_Specification_V10.pdf (last accessed 9 May 2013)
\textsuperscript{127} http://www.nice.org.uk/CG87 (last accessed 9 May 2013)
and guidance rather than stand-alone comparators that may encourage short-term savings that could have unintended costly consequences.

4. **It is critical that we align how we measure and incentivise health-care professionals (& NHS England bodies) with national clinical guidelines on long-term condition risk factor management in order to address mortality rates and quality of life**

4.1 Inconsistencies exist in national guidance for treating patients and how GPs are incentivised:

4.1.1 For example, in the NICE Type 2 Diabetes Guideline (CG 87)\(^{130}\) it states, “Consider intensifying cholesterol-lowering therapy (with a more effective statin or cholesterol absorption inhibitor) in line with NICE guidance if there is existing or newly diagnosed cardiovascular disease, or if there is an increased albumin excretion rate, to achieve a total cholesterol level below 4.0 mmol/litre (and HDL cholesterol not exceeding 1.4 mmol/litre) or an LDL cholesterol level below 2.0 mmol/litre.”\(^{131}\)

4.1.2 However, the Quality Outcomes Framework that incentivises GP states: The percentage of patients with diabetes, on the register, whose last measured total cholesterol (measured within the preceding 12 months) is 5 mmol/l or less and has an activity threshold of 40–75%.\(^{131}\)

4.1.3 The European Society of Cardiology/European Atherosclerosis Society Guidelines are even more stringent than UK NICE guidelines for very high risk patients, they recommend an LDL-C goal of 1.8 mmol/litre and/or 50% reduction when target level cannot be reached.\(^{132}\)

4.2 The impact of factors on quality of life & productivity (such as the potential impact of hypoglycaemia in Type 2 diabetes) should be recognised, researched and acknowledged within NHS measures of long-term condition management quality throughout the system.

4.2.1 For example, DVLA guidelines\(^{133}\) state for people with diabetes when treated with medication other than insulin which carries a risk of inducing hypoglycaemia (including sulphonylureas and glinides), the following standard applies in order to retain a driving licence:

**Class 2 Drivers (buses and lorries)**

— There has not been any severe hypoglycaemic event in the previous 12 months.

**Class 1 Drivers (cars and motorcycles)**

— Must not have had more than one episode of severe hypoglycaemia within the preceding 12 months.

The impact of hypoglycaemia on a person who is a professional driver or who drives regularly could be very significant on both quality of life and productivity if hypoglycaemia leads to losing their licence.

Similarly, in the elderly even a mild episode of hypoglycaemia may lead to adverse outcomes in frail elderly patients. For example, episodes of dizziness or weakness increase the risk of falls and fracture.\(^{134}\)

The NICE Quality Standard for Diabetes\(^{135}\) recognises the importance of hypoglycaemia and includes a measure that states: “People with diabetes who have experienced hypoglycaemia requiring medical attention are referred to a specialist diabetes team”.

Quality measures recognising factors such as hypoglycaemia monitoring and/or management, should also be incentivised in QOF and CCG Outcome Indicators.

5. **Quality measures need to go beyond “testing” alone to ensure risk factors are being effectively addressed nationwide and to further narrow inequalities**

5.1 Although testing, such as the nine Key Care Processes for Diabetes, are important testing alone cannot make a difference to outcome, healthcare professionals need to ensure action is taken on the results of tests to ensure that people’s long-term condition and risk-factors are being managed effectively.\(^{136}\) Quality measures and outcome indicators throughout the NHS system (eg CCG outcome indicators) should reflect this.

5.2 For example in diabetes, even where testing is taking place, many patients are not achieving the recommended target range for risk factors (eg although 90% of Type 2 Diabetes patients are having their HbA1c and cholesterol tested, only 60% are achieving target HbA1c levels and only 40% are achieving their target cholesterol level in England)\(^3\).

\(^{130}\) http://www.nice.org.uk/CG87 (last accessed 9 May 2013)

\(^{131}\) w.bma.org.uk/-/media/Files/PDFs/.../Contracts/gpqofguidance20132014.pdf (last accessed 9 May 2013)


\(^{133}\) http://www.dft.gov.uk/dvla/medical/Annex%203%20changes%20to%20diabetes.aspx (last accessed 9 May 2013)

\(^{134}\) Marker J C, Cryer P E, Clutter W E. Attenuated glucose recovery from hypoglycemia in the elderly. Diabetes 1992; 41: 671–678

\(^{135}\) http://www.nice.org.uk/media/FCF/87/DiabetesInAdultsQualityStandard.pdf (last accessed 9 May 2013)

5.3 Access to education of the patient and care planning is of paramount importance.\textsuperscript{137} A patient should be informed and enabled to take a role in self-management of diabetes risk-factors and understand factors such as the importance of optimal blood glucose control in order to avoid serious complications.

6. With the creation of NHS England and the removal of certain information & education structures (eg NHS diabetes) it is key that new support structures are adopted rapidly in order to offer practical assistance to commissioners

6.1 With the dissolution of NHS Diabetes, there is a gap in support & education for development of commissioning for diabetes services at the very time when it is most needed.

6.2 There are a wide number of data sets available for CVD and diabetes but they are often difficult to interpret and support is required on how to utilise these and help in practical implementation of commissioning.

7. There are a number of examples of effective integration of services across health, social care and other services which treat and manage long-term conditions

7.1 First Diabetes (Derbyshire) is a current of example of how integrated care can provide real improvements in care for diabetic patients, whilst reducing admission rates.\textsuperscript{138}

7.2 See earlier example of EiP\textsuperscript{9} example, paragraph 3.2.1.

8. With an increasing ageing population it is key that more is done to address disease management of long-term conditions in the community-setting in order to improve mortality rates, quality of life and prevent costly hospital admissions and care. This should be supported by appropriate measurement and outcome indicators

8.1 Diabetes cost approximately £23.7 billion in the UK in 2010–11: £9.8 billion in direct costs (£1 billion for Type 1 diabetes and £8.8 billion for Type 2 diabetes) and £13.9 billion in indirect costs (£0.9 billion and £13 billion). In real terms, the 2035–36 cost is estimated at £39.8 billion: £16.9 billion in direct costs (£1.8 billion for Type 1 diabetes and £15.1 billion for Type 2 diabetes) and £22.9 billion in indirect costs (£2.4 billion and £20.5 billion).\textsuperscript{139}

8.2 It is key that there is a shift in focus from short-term cost-cutting in the community-setting to more efficient use of NHS resources, by effective prevention, diagnosis and risk-factor management to avoid costly complications and hospital treatment. This should be supported by appropriate measurement and outcome indicators.

9 May 2013

Written evidence from the MND Association (LTC 25)

Summary

— The ongoing implementation of the NHS reforms makes assessing the NHS’s capabilities to provide care for people with long term conditions challenging; in particular, commissioning services for people with long term neurological conditions is not currently the clear responsibility of either CCGs or NHS England.

— Unplanned admissions to hospital of people with long term conditions have risen above the NHS average, despite an increase in funding; this appears to be the end result of manifold problems with providing care for people in their own homes.

— The design and commissioning of services for people with long term conditions is a longstanding problem within the NHS, which prompted the establishment of Neurological Commissioning Support and other similar organisations.

1. Introduction

(i) Few conditions are as devastating as motor neurone disease (MND). It is rapidly progressive in the majority of cases, and is always fatal. People with MND will, in varying sequences and combinations, lose the ability to speak, swallow and use their limbs; the most common cause of death is respiratory failure. Most commonly the individual will remain mentally alert as they become trapped within a failing body, although some experience dementia or cognitive change. There are about 5,000 people living with MND in the UK. Half of people with the disease die within 14 months of diagnosis. There is no cure.

(ii) MND is therefore unusual for a long term condition: it is not a disease with which someone typically lives for a substantial period of time; its severe and unpredictable nature makes self-management challenging,
and requires the regular involvement of large numbers of health and social care professionals; and therapies to extend life and reduce symptoms are limited in both number and effectiveness.

(iii) Furthermore, this is a difficult time at which to assess the capacity of the NHS and social care system to meet the needs of people with long term conditions. While most of the NHS reforms in England came into effect in April, the reforms to specialised commissioning, which will provide services to many people with LTCs are not due to come into effect until October.

(iv) At present it is unclear which services for people with MND, and people with other neurological conditions will be commissioned on a specialised basis by NHS England, and which are to be the responsibilities of CCGs. The draft service specification published for consultation in December by NHS England suggested a radical new model in which all neurology services, including community services that had been widely expected to remain with CCGs, would be commissioned on a specialised basis. However, this has yet to be confirmed as definitive (and indeed seems unlikely to be, as NHS England’s commissioning budget is almost certainly too small to pay for such a large range of services): while we await clarity on specialised commissioning, some CCGs appear to have taken note of the proposal and not commissioned any neurology services at all. Currently therefore people with long term neurological conditions appear to be nobody’s responsibility. With the new system still just over a month old, the consequences for the services that people with MND rely on have yet to become clear.

2. TREATING MORE PEOPLE OUTSIDE HOSPITAL

(i) We have long urged that services for people with MND be improved in order to be more preventative in character. With appropriate support, including home modifications and respite care, people with MND can usually be cared for most appropriately in the home. Yet the National Audit Office’s report “Services for people with neurological conditions” of December 2011 showed that unplanned admissions of people with MND to hospital have been rising at above the rate of increase for the NHS as a whole (31% from 2004–05 to 2009–10 compared to 20%), despite a 37% real-terms increase in annual health spending on neurological services between 2006–07 (£2.1 billion) and 2009–10 (£2.9 billion). More effective investment in caring for people with MND in the home would save the costs of these growing numbers of hospital admissions.

(ii) The problems reported by people with MND in respect of their support at home are myriad. A lack of care plans, integrated care or specialist nurses may be the issue; alternatively, respite care may not be available, placing huge burdens on regular carers; community support workers (nurses or social workers) may not be trained in helping people to manage non-invasive ventilation (NIV) or a gastrostomy (PEG, PIG or RIG); a stay in hospital to fit a PEG, for instance, might be prolonged by the absence of a social care package to allow the person to be discharged safely; specialised equipment for mobility, communication and environmental control may be provided or modified far too slowly, leaving the individual at risk, for instance, of falls. Provision of all of these things is hugely variable across England, although the low prevalence of MND and the highly localised nature of provision makes quantifying the impact of any individual one of these very hard; the disturbing rise in unplanned hospital admissions already noted remains the best indicator that there are problems.

3. ASSISTANCE AVAILABLE TO COMMISSIONERS

(i) We believe that there are long-standing problems with the design of services to support community-based care for people with long term neurological conditions. Alongside the MS Society and Parkinson’s UK we founded Neurological Commissioning Support (NCS) to provide exactly this type of support to NHS commissioners. Since then, charities in several other disease areas have indicated their intention to establish equivalent services. It must be emphasised that NCS was established as a result of failure by the NHS to commission services for people with long term neurological conditions of a sufficiently high quality. That said, NCS can only work where they have been commissioned to work; it cannot support every part of the NHS at the same time.

(ii) Additionally, the MND Association’s Regional Care Development Advisers support commissioners to design and commission appropriate services. However, with 22 RCDAs in England, we cannot provide in-depth support to all 211 CCGs.

(iii) We do not have information about the abilities or offerings of the new Commissioning Support Units (CSUs) in respect of neurology.

4. THE PATIENT AS A PERSON, NOT A CONDITION

(i) It is a positive development that the view that a patient should be seen as an entire person and not merely as a single diagnosis has become an orthodoxy in health policy. We would however suggest one caveat: it risks overlooking the significance of a catastrophic diagnosis such as MND, where in all but the rarest cases the fact that a person has MND is the single most important piece of information about them, from a care perspective. A failure to grasp the significance of the diagnosis is highly likely to lead to inadequate care.
5. IMPLICATIONS OF THE AGEING POPULATION

(i) Although any adult can develop MND, it is more common in older people. As the population ages, we can therefore expect to see more people with MND. We have estimated that there will be an increase in numbers of people living with MND of 27% from 2012 to 2020. This would bring the figure to approximately 6,350.

8 May 2013

Written evidence from the Association of Directors of Adult Social Services and the Local Government Association (LTC 26)

BACKGROUND

ADASS

The Association of Directors of Adult Social Services (ADASS) represents Directors of Adult Social Services in Local Authorities in England. As well as having statutory responsibilities for the commissioning and provision of social care, ADASS members often also share a number of responsibilities for the commissioning and provision of housing, leisure, library, culture, arts, community services and increasingly, Children’s Social Care within their Councils.

LGA

The Local Government Association (LGA) is the national voice of local government. We work with and on behalf of our membership to promote support and improve local government. The 422 authorities that make up the LGA cover every part of England and Wales. Together, they represent over 50 million people. They include county councils, metropolitan district councils, English unitary authorities, London boroughs, shire district councils and Welsh unitary authorities, along with fire authorities, police authorities, national park authorities and passenger transport authorities.

RESPONSES

The scope for varying the current mix of service responsibilities so that more people are treated outside hospital and the consequences of such service re-design for costs and effectiveness

There are strong and widely acknowledged arguments for disinvesting from acute services and reinvesting into community settings. However, a number of barriers restrict these opportunities. The financial models of Payment by Results and the tariff system, which reward acute activity, actually incentivise hospital trusts to maximise service take-up.

More fundamentally, it is beginning to be accepted that there are too many hospitals now, particularly those based on the traditional District General Hospital model, given the developments in primary, community and social care. The challenges to resolving this are considerable; simply downsizing a hospital’s activity in order to reduce acute funding is rarely an option, as issues of clinical safety and the required staffing levels for accreditation of services rapidly emerge. The real alternatives of reconfiguration and changing the roles of local groups of hospitals have always proved immensely difficult to engineer against public resistance.

These barriers are further heightened by significant budget pressures within the whole system, limiting the opportunity to switch funding or develop community based facilities in advance of reducing acute demand.

One way forward would be to create a tariff system for acute care which included the full end-to-end care pathway, pre-admission and post discharge, in order to incentivise a more holistic approach to clinical commissioning and service development.

Supporting this, reforms of health and social care are pushing for greater integration, placing a stronger emphasis on prevention and early intervention and promoting a system-wide focus on improved outcomes for the individual set with an individual and local community asset based approach.

The emphasis over the past period has been on speedier discharge, but as set out above this needs to shift to prevent unnecessary admissions, sign posting people to other services, plus providing a range of “off the shelf” services which would potentially support people to avoid unnecessary admissions to in-patient care ie 24/7 access to telehealthcare, homecare, respite etc, without requiring in depth and bureaucratic assessments.

The Community Budget areas have shown us that this will require a joined up approach to leadership and shared cultures across the health and care system as well as sharing of individual data records so that people can be tracked and supported across the system.

In addition to improved tariff and incentive mechanisms, local areas will need to take a joint approach to the use of resources and develop joined up commissioning arrangements and to make sure that resources are shifted from acute to preventative and community based services. Health and Wellbeing Boards (HWBs), as the body with statutory responsibility to promote integration, will be crucial in holding the system together locally, promoting joined up working and enabling the best use of resources locally.
The LGA strongly supports this issue being addressed. It also features strongly in emerging Health and Wellbeing Boards’ priorities. We recognise too the political impact for councillors, MPs, Scrutiny and Healthwatch partners.

The readiness of local NHS and social care services to treat patients with long-term conditions (including multiple conditions) within the community

Social care and the NHS have been working closely over a long period of time and there are many examples of integrated community-based services and support. These models and variations can readily be adapted to suit the management of long term conditions. The current reforms are helping to accelerate the pace and scale of these approaches with the Health and Wellbeing Boards being a new element in bringing local partners together to address local need. The shift of Public Health responsibilities to councils alongside the development of an integrated Outcomes Framework are catalysts to making community-based integrated approaches the norm.

ADASS and the LGA are currently working closely with five other national partners (NHS England/DH/ PHE/Monitor/ADCS) through an Integrated Care Working Group (ICWG) to support the acceleration of the pace and scale of integrated community-based preventative and early intervention services and support. This work is reporting directly to the Care Services Minister and the partnership is considered a significant step.

Equally, the development of Personal Health Budgets for all those with Continuing Healthcare funding provides an opportunity for personal budgets to be developed jointly with social care, pooling resources based on an individual need, which potentially could lead to the development of more clinical support, which may be more appropriate, deliver better outcomes and at reduced cost—arguably this is already happening in many areas. The real benefits will come by extending this approach beyond CHC eg mental health needs and support provided by local community groups or third sector organisations rather than medically led psychiatric services.

One of the key messages for the NHS and social care working together to support those with long-term conditions is that integrated services must be designed from the bottom up, designed around integrated health and social care personal support plans and the pathways of people through a local health and social care system.

It is not sufficient to develop joint services based purely upon organisational, managerial or structural integration. There needs to be a holistic and whole-system approach.

Successful and sustainable re-design requires the full engagement of front-line staff, managers, people who use services and their carers. There also has to be cultural change across organisations, facilitating multi-disciplinary working.

The practical assistance offered to commissioners to support the design of services which promote community-based care and provide for the integration of health and social care in the management of long-term conditions

The ICWG is setting a “Common Purpose Framework” (CPF) to describe the barriers to integration and establish national and local enablers to overcome these barriers. This will include commissioning guidance. ADASS is working with the Kings Fund to produce guidance for Health and Wellbeing Boards in integrating commissioning activity. ADASS is also supporting and promoting a leadership programme to help Directors in their role in taking forward integration of commissioning and service provision.

Arguably much of the work already being progressed with Personalisation and Think Local Act Personal(TLAP) promotes an approach which moves away the “professional gift” model—diagnosis and labels, to service users determining their needs and priorities, based on the outcomes they want to achieve and arranging the support that they require and how it is provided. There are many major national, regional or local third sector organisations working with people with long-term conditions and they will no doubt make their own submissions. Particularly at national level, they can be a valuable source of research into service integration, improved outcomes and examples of best practice from across the country.

The numbers of people dying in hospital has continued to rise whilst a number of surveys indicate that, given a choice, a large majority of people would choose to be cared for at home. Recent research by the Nuffield Trust reaffirmed the inter-relation of health and social care at the end of life and the need to provide a holistic approach focused around the individual and their needs and wishes. Social services have access to and make best use of local intelligence (health and social care data sets) to focus on the design and delivery of end of life care improvements in all sectors. Engagement with the emerging clinical consortia, commissioning support organisations and health providers across acute and primary care settings, local hospices and local authorities is well developed to ensure the effective pooling of resources to facilitate the commissioning and design of new services with a clear understanding of the shared service improvement agenda.

Finally, however, as noted above, the real-life experience of staff, patients and carers is an essential element of service re-designs and commissioners must access this experience as much as possible.
The ability of NHS and social care providers to treat multi-morbidities and the patient as a person rather than focusing on individual conditions

ADASS and the LGA have the longest history of promoting personalisation within the public sector, which considers “outcomes” over treatment, conditions and models of service. This is reflected in the three outcomes for the NHS, Public Health and Adult Social Care, which can guide providers. Personalisation is being complemented by outcome-based commissioning and more recently by the development of payment by results. These are driving a person centred approach.

Both the LGA and ADASS have supported National Voices and “Think Local Act Personal” in the development of a narrative for integrated care an support, driven by patients and service users, that will help commissioners and providers to understand and respond to the needs of real people.

The ability to treat patients as people first is critically dependent upon the quality, skills and stability of the health and social care workforce. In respect of supporting people with long term conditions in the community, there is a great deal of guidance available for staff involved in personal care of any kind. One example would be the “Common Care Principles for Self-Care” developed by Skills for Health and Skills for Care, supported by ADASS through the Workforce Development Network. Alongside the Workforce Development Strategies of the Department of Health and Skills for Care, ADASS has prompted the development of integrated workforce strategies at a local level (initially known as Integrated Local Area Workforce Strategies). Minimisation of staff turnover, as one example of a benefit, promotes continuity of carers on teams of carers for people, which in turn promotes greater dignity in the care arrangements.

Taking a truly person centred approach to LTCs means changing the paradigm, so that people who use services are given more control of co-ordination and are expected and helped to take more responsibility for self-management. Coordinate My Care for end of life care seems a good example and has led to real shifts in practice and better outcomes. Alongside this, there are some real opportunities to use technology to help manage LTCs more effectively. This includes some of the “diagnostics” in telehealth but also some simple ways of being able to communicate regularly and frequently with people who use services. The infrastructure of telecare has a lot to offer here.

The concept of “pathways” can be as much of a hindrance as a help. By definition many people who use adult social care have several conditions, so then flooding them with specialists each with their own pathway to follow just makes life more complicated. ADASS and the LGA would suggest that, we keep the core benefit of a “pathway” which is consistent and evidence based decision making but have health and support plans much more based on the person.

Finally it is important to recognize the psychological aspects of these (long term) conditions and to ensure that a support plan takes account of this: depression for example is a major determinant of how an out of hospital support plan works.

Obesity as a contributory factor to conditions including diabetes, heart failure and coronary heart disease and how it might be addressed

The movement of Public Health to local councils alongside the adult social care focus upon wellbeing is creating the right conditions to bring the totality of local resources to bear upon health inequalities and its causes. DASSs and Lead Members have generally a broad portfolio of services (often including leisure, housing and others) to draw upon and deal with these challenges, particularly around prevention and social inclusion.

Social care services can support the reduction of obesity by always having regard to good nutritional advice and the benefits of any level of physical exercise or activity in both care planning and in service delivery. Awareness of nutritional issues is particularly important where a person may have some degree of restricted mobility. Training in these areas for personal support planners would be beneficial, as would access for people with LTCs to local health promotion services. There have also been many examples across the country of councils working with the former Primary Care Trusts to develop “Leisure Centre Prescription Schemes”, and tackling obesity should be a shared prevention priority between councils and Clinical Commissioning Groups.

Obesity certainly features in Joint Strategic Needs Assessments, and is likely to be a priority in the Joint Health and Wellbeing Strategies which have been developed. These will in future be supported and monitored by the HWBs.

Current examples of effective integration of services across health, social care and other services which treat and manage long-term conditions

There are multiple examples within social care where personalisation and use of personal budgets has led to a significant change both in improving the outcomes people are achieving, changes in the services and support they are accessing and the positive impact it has had upon their perceptions and experience. The Personal Budget Outcome Evaluation Tool (POET) survey 2011 and associated report (attached in a link at the end of this submission) provides significant evidence based on individuals’ experiences and examples.

Best practice in end of life care within local authority services includes working with a wide range of stake holders such as hospices local colleges, social care providers including care homes, extra care schemes,
domiciliary providers and supported living establishments. These networks have allowed commissioners to develop innovative approaches and interventions to support a range of service user groups. The recent publication of the National End of Life programme “Sharing successful strategies for implementing supporting people to live and die well” highlights good practice across England demonstrates how effective integration can be to support people with long term conditions and in particular those people nearing the end of their life.

There is a 30 year tradition of multi-disciplinary working in the Community Mental Health Teams and Community Learning Disability Teams developed initially to support the closures of long-stay hospitals from the late 1970s, early 1980s and beyond. Much of the learning from these teams, in terms of differing professional cultures, the need for joint training, addressing different assessment systems and processes, is still relevant today in developing integrated working.

In general terms, there are many current examples of integrated working, which will include services for people with LTC’s. Torbay has often been cited for its integrated community health and social care services, and North East Lincolnshire remained the only “Care Trust Plus” in the county, with adult social care services delivered within the NHS on behalf of the council. In Greenwich, the Royal Borough has developed award-winning integrated services with the community health services of the Oxleas Foundation Trust. These are based on a single point of access, a joint emergency response, integrated hospital discharge teams, community assessment and rehabilitation teams and intermediate care at home teams. In respect of long-term conditions, there is clear evidence of improved quality of life, with reductions in emergency admissions and outpatient appointments (as well as significant financial gains).

The implications of an ageing population for the prevalence and type of long term conditions, together with evidence about the extent to which existing services will have the capacity to meet future demand

The ADASS Budget survey shows 3% demographic pressures (about £400 million pa), with services being stretched, with fewer people receiving services but at higher cost and intensity. This points to an urgency to consider a whole system approach facilitating switching resources from acute to primary preventative services. Unlike when the NHS was set up 65 years ago, now more than half of GP appointments and two-thirds of outpatient Accident and Emergency visits are for people with long-term illnesses and conditions.

This group, many of whom are older people, are now responsible for 70% of the total health and care budget, over £70 billion every year and that number is growing. Equally, when discussing the aging population we naturally concentrate on the older age group, but there are also similar issues with substantial growth in younger people with significant disabilities living much longer, which is fantastic, but presents equally significant challenges in the support they require.

A major element of the growing demand for services to older people is the increased prevalence of dementia. This need and the necessary response are comprehensively covered in the National Dementia Strategy, to which ADASS and LGA contributed. It is clear that the progression of dementia can be slowed and early diagnosis magnifies the benefits of any subsequent intervention. The National Dementia Strategy takes a social model of disability: so “living well” does not really rely over much on health services and recognises the importance of housing, technology, combating stigma, dementia friendly communities, asking the wider community what it can do. Another proposal would be to involve the Design Council in innovation.

Finally, there is a need to recognise increases in demand for services for people who suffer strokes, diabetes and cardiovascular conditions. Timely and expert treatment can increase longevity, limit disability and promote quality of life.

The interaction between mental health conditions and long-term physical health conditions

The correlations between long-term and various aspects of mental health, particularly depressive illnesses are well-known. This can lead to a self-perpetrating set of interactions such as social withdrawal and reduced mobility, self-neglect, poor nutrition or increasing problems with smoking, drugs or alcohol.

The interaction of mental health conditions and long-term physical health conditions is well evidenced and reflected in the mental health strategy “No health without mental health”. Poor mental health has a negative impact on people’s long term health care needs and it is estimated that people with long term conditions are two to three times more likely to experience mental health problems than the general population.

Evidence suggests that there is a strong negative impact on recovery and management of long term conditions for those people who also have mental health needs. This manifests itself in longer periods of time spent in hospital, poor outcomes and lower quality of life. If mental health problems are left untreated, this will also impact negatively on people’s ability to self-manage their long term condition (such as diabetes) with people lacking the motivation and ability to do this.

What is needed is strong collaboration between primary and mental health care with services wrapped around the person rather than conditions. ADASS has worked with the Royal College of Psychiatrists to produce a position paper calling for pooled personal budgets alongside integrated assessments across NHS and social care, and integrated support plans. Ideally this could support both the mental health and physical health needs of individuals.
Ev  w58  Health Committee: Evidence

The extent to which patients are being offered personalised services (including evidence of their contribution to better outcomes)

In many respects, the introduction of the Independent Living Fund (ILF) in 1988 could be seen as a major early milestone in the development of a personalised approach to supporting disabled people. Well ahead of the community care reforms, the introduction of Direct Payments and a commitment to universal availability of personal budgets, the ILF allowed people to create their own personalised care arrangements using direct purchasing power. The ILF has contributed to major developments such as the support for employment of Personal Assistants, and the role of user-led organisations in advocating for, supporting and providing local services.

The personal budgets approach is ideal for support for people with LTCs, allowing greater choice and control of care arrangements. Long-term conditions were a natural focus for the piloting of Personal Health Budgets.

It is arguable that the recent review of ILF has concluded that given the progress of personalisation and prevalence of personal budgets in adult social care, ILF Funding should transfer to LAs to be managed in a single approach based around the individual. Arguably this would also provide LAs the opportunity to review and revise the allocation of such resources based on need.

Attached to this response is a link to the 2011 National Personal Budget Survey published by TLAP.
http://www.thinklocalactpersonal.org.uk/_library/Resources/Personalisation/Personalisation_advice/2011/POET_surveys_June_2011_-_EMBARGOED.pdf

The 2012 version will be published at the end of May. Below is an excerpt from the executive summary for the 2012 National Personal Budget Survey:

“There is an increasing body of evidence across health and social care that personal budgets have the potential to improve social care and well-being outcomes, for people with long term conditions. This was the clear conclusion of the Personal Health Budgets pilot independent evaluation published in late 2012 and is consistently demonstrated in social care by councils using the Personal Budgets Outcomes Evaluation tool (POET). It will be important to take personal budgets forward across health and social care as a key element of the integration agenda in support of people with long term conditions”.

8 May 2013

Written evidence from the Urology User Group Coalition (LTC 27)

INTRODUCTION

1. The Urology User Group Coalition (UUGC) welcomes the opportunity to respond to this inquiry into the management of long term conditions (LTCs).

2. The UUGC represents the estimated half a million continence appliance users who rely heavily on urology products and services to maintain their health and wellbeing. We are also representative of many people with the vast range of clinical diagnoses that usually require continence management to be integrated into care and treatment pathways. These include the LTCs of cancer, stroke, spinal cord injury, MS, spina bifida, Parkinson’s disease, and other neurological conditions.

3. The UUGC is particularly keen to raise points relating to the readiness of local NHS and social care services to treat patients with LTCs within the community; the practical assistance offered to commissioners to support the design of services; the ability of NHS and social care providers to treat the patient as a person; current examples of effective integration; and the extent to which patients are being offered personalised services.

The readiness of local NHS and social care services to treat patients with LTCs within the community

4. The majority of care for people with continence needs is provided in the community, though there are a number of issues which are set out below.

5. People with a wide range of LTCs have to deal with bladder and/or bowel dysfunction as a part of their condition. This aspect of their care is not always well-managed, with problems typically caused by the unsuitable or inappropriate provision of products (such as catheters, urinary sheathes, and leg bags) to manage incontinence or other causes of bladder dysfunction. Given the heterogeneity of people affected, there are a great many individual needs and requirements to cater for.

6. Apart from specialist nurses, the healthcare professionals responsible for prescribing products, including GPs and non-specialist nurses, often do not have a good knowledge of the available products and their differences, meaning that they are often ill-placed to advise patients on how to best manage their condition. GPs and non-specialist nurses should be encouraged to refer patients to specialists and to more actively discuss continence issues with patients, which all involved may be reluctant to do due to the sensitive nature of the topic.
7. Significant numbers of users of continence products have indicated to the UUGC that they had experienced problems accessing the products which best met their needs, with users also suggesting that they felt their GP or nurse did not always work with them to find the best product to suit their needs, and with many saying they did not feel their GP or nurse was well-informed about the available products.

8. The UUGC recommends that specialist nurses are best-suited to ensure patients receive proper advice on how to best manage their condition, and to work with patients to find the best product to suit their needs. In particular, the UUGC recommends that each clinical commissioning group and Health and Wellbeing Board publish a strategy setting out how they will train healthcare professionals to provide appropriate advice and support to patients with long term conditions, reflecting on their continence needs.

The practical assistance offered to commissioners to support the design of services

9. Individuals should be able to access any product listed on Part IX of the Drug Tariff, which covers the provision of stoma and urology appliances. The Drug Tariff is maintained as a national list of products which have been assessed as both clinically and financially appropriate, with a set price for reimbursement determined at a national level.

10. The UUGC supports the existence of the Drug Tariff, and is concerned that the list should continue to be maintained as a national list from which local commissioners cannot create formularies or other restrictions leading to a “postcode lottery”.

11. A system whereby products are reassessed by local commissioners and placed onto a formulary, will often lead to a more narrow selection of products compared to what is available on the national Drug Tariff. Such a system involves substantial bureaucracy and it is hard to understand what value is added to patients or the health service by both national and local evaluations of clinical or financial effectiveness.

12. In addition, if companies which produce continence devices have to face a further set of regulatory hurdles, it acts as a barrier to innovation which means that patients may face delays in receiving products more suitable to their needs than the ones they currently use.

13. Local commissioners should be supported to understand the need for patient choice in continence products, and recognise the impact the unsuitable products may have on patients, and on the wider health service. In particular, the UUGC notes that unsuitable products may cause serious discomfort or loss of dignity. Less-than-optimal products can also limit the ability for an individual to care for themselves and increase their reliance on others.

14. People with unsuitable continence products may also place an increased burden on the health and social care services, which may be entirely avoidable. For example, unsuitable products may lead to urinary tract infections, which cost the NHS in staff time and money to treat, and involve unnecessary disruption for the patient.

15. A July 2011 publication by the Department of Health regarding Any Qualified Provider for continence services noted that poor continence care could lead to unnecessary catheterisation, associated UTIs and pressure ulcers, which is the cause of 51,000 hospital admissions in 2008–09, with an estimated cost to the NHS of between £1.4 billion and £2.1 billion each year. The same publication noted that small improvements in the service could potentially result in great savings across the wide health economy and beyond.

16. The UUGC recommends that NHS England provides advice to local commissioners on the importance of patients being able to access appropriate medical devices (including continence devices), and when reviewing how healthcare organisations manage UTIs, consider whether limitations on access to appropriate medical devices was a contributing factor.

The ability of NHS and social care providers to treat the patient as a person; and the extent to which patients are being offered personalised services

17. The UUGC welcomes the legal requirements in the Health and Social Care Act 2012 on many new health bodies which require them to have regard to the NHS Constitution. However, the UUGC is keen to ensure that this is not simply a checkbox exercise, but leads to a real culture change throughout the NHS whereby healthcare professionals actively involve patients in decisions about their care, in particular listening and responding to patients’ feedback about the appropriateness of the continence devices they are prescribed.

18. Many continence service providers do offer excellent services to patients with continence issues, which are individually tailored to their needs and preferences. When specialist nurses are available to discuss with patients their issues and concerns it not only makes it more likely that wastage of products and unnecessary UTIs are avoided, but that the patient is able to maintain their dignity.

19. Conversely, people who have struggled with inappropriate products due to short-term decision making are evidence of poor ability amongst healthcare providers to treat the patient as a person. The UUGC is aware
of numerous examples where patients struggle with avoidable continence needs such as an inability to self-catheterise with a particular product or operate a particular type of drainage tap, when alternative products exist the individual could simply and happily manage.

20. **The UUGC recommends that best practice is effectively shared throughout the NHS regarding treatment and support for patients with long term conditions, monitored by patient feedback, and that NHS England keep under review the support provided to healthcare professionals in areas with lower levels of patient satisfaction.**

**CONCLUSION AND RECOMMENDATIONS**

21. In conclusion, the UUGC would seek to draw the Health Committee’s attention to the need for commissioners to be properly supported in understanding patients' need for products which are suited to them, and the need for specialist healthcare professionals to discuss issues with patients. The UUGC is strongly in favour of a national list of products and against restrictions which limit patient choice.

22. To address these points, the UUGC makes three recommendations:

23. **The UUGC recommends that specialist nurses are best-suited to ensure patients receive proper advice on how to best manage their condition, and to work with patients to find the best product to suit their needs. In particular, the UUGC recommends that each clinical commissioning group and Health and Wellbeing Board publish a strategy setting out how they will train healthcare professionals to provide appropriate advice and support to patients with long term conditions, reflecting on their continence needs.**

24. **The UUGC recommends that NHS England provides advice to local commissioners on the importance of patients being able to access appropriate medical devices (including continence devices), and when reviewing how healthcare organisations manage UTIs, consider whether limitations on access to appropriate medical devices was a contributing factor.**

25. **The UUGC recommends that best practice is effectively shared throughout the NHS regarding treatment and support for patients with long term conditions, monitored by patient feedback, and that NHS England keep under review the support provided to healthcare professionals in areas with lower levels of patient satisfaction.**

**LIST OF UUGC MEMBERS**

| — Back Up Trust.          |
| — Bladder and Bowel Foundation. |
| — ERIC.                     |
| — Multiple Sclerosis Trust. |
| — PromoCon.                 |
| — Shine.                    |
| — Spinal Injuries Association. |
| — Urostomy Association.     |

8 May 2013

**Written evidence from Mrs Christine Talbot (LTC 28)**

I am a State Registered Nurse and Lymphoedema Practitioner, specialising in the care and practice of lymphoedema management in the Dorset area for seven years.

I see a wide range of patients with both primary and secondary lymphoedemas, lipoedemas and combined pathologies. Secondary lymphoedemas are as a result of surgery, trauma or chronic illnesses.

In the main patients pay privately for their treatment; until recently a few had Primary Care Trust funding, funding which has now been withdrawn, regardless of necessity. As yet no funded care package has been implemented in its place by the individual General Practitioner surgeries, District Nurses claim they cannot offer such specialised treatment, neither would they have the time to do so, thus as a traditional “Nightingale” nurse, I am treating clinically dependent lymphoedema patients for free.

Equally patients on social benefits or very limited incomes and other specific financial short falls, are seen on a reduced rate, treatment is paramount to their well being, without which they could incur all manner of complications, infection, chronic pain and associated disabilities. Ironically, without my clinical lymphoedema skills, these patients would come under the NHS financial umbrella and receive costly inappropriate care and medication for their condition.

In general the NHS has neither the training, the interest, nor sufficient knowledge of lymphoedema and its multifaceted complexities, nor any realistic understanding of ongoing, lifelong dependency on healthcare. A
few NHS or charity associated Lymphoedema Clinics offer a limited service of six monthly limb measurements appointments and supplying of hosiery.

I would advocate,

— All trainee doctors and nurses receive comprehensive education in the lymphatic system and associated disorders and diseases affecting that system and immune function and failure overall.

— Individual lymphoedema trainee schools should be inspected, regulated and stricter emphasis placed on clinical knowledge and skills prior to trainee acceptance.

— Patients should not have to self fund such long term clinical treatment.

— Any patient receiving funded intensive treatment in specialist units on limited time spans must have in place prior to admission, a comprehensive lymphoedema specific, care package and management programme within their NHS community on discharge.

I look forward with interest to the outcome of the House of Commons Inquiry into long term conditions and care requirements. So too, as to whether there will be future opportunity and funding for education and enlightenment with regards to a most debilitating, clinically complex and socially and psychologically demanding and depressing condition for those afflicted.

8 May 2013

Written evidence from Doreen (LTC 29)

LYMPHOEDEMA

LONG TERM CONDITION

I am 59 and suffered with lychin schrosis most of my adult life which unfortunately turned to cancer of the vulva three years ago. I had a radical surgery and had all my lymph glands in my groin removed. I now have secondary lymphoedema in my groin and legs. My cancer has gone but left with this awful condition which needs to be controlled every day.

When in hospital was given a sheet of paper with dos and don’ts about lymphoedema. These were very upsetting re: not have very hot bath, not to shave legs, not to get stung on leg due to contacting celuitis, not to have injections in legs etc.

My cancer nurse who was on the telephone at my beck and call was marvellous as was my Doctor, nothing was too much trouble for them both to help me in any way.

Had pain in groin and was told to telephone lymphoedema department in Dorchester Hospital. You leave a message and someone gets back to you straight away as this condition can be very serious if things go wrong.

Had appointment and had legs measured and told had lymphoedema and stockings were ordered as did not want tights as very hard to put on and have arthritis coming in fingers. Was not impressed with the nurses manner, which was hard luck, wear your compression garments and what’s the matter with them, and you just have to get on with it. I go every 6 months and earlier if need be, have my legs measured to see if condition has got worse and every time I come away I feel really down and cry.

I feel like an old woman trussed up with all that I have to wear to keep the fluid moving.

At the lymphedema department there are hundreds of leaflets on breast care but a handful about the condition in your legs.

I am a member of lymphoedema support group (yearly subscription fee) and surf the net for any information and guidance for help for this condition.

My daughter was talking to her friend about my condition and she recommended a friend of hers who does massage for this condition. She has been my life saver, told me so many things to do to help my condition. I go to her privately every month for massage which is keeping it under control. I would go more frequently but lost my job after my operation and cannot afford to go more regularly as it costs £70 but I get a discount for £50. Before Christmas had a very stressful time with my Mother in Law and sadly she died. I had fluid build up all around my breasts which was so painful and needed to wear vest like compression to push fluid away. Apparently stress can cause this and Christine my massage lady was really worried about my condition as it can affect your breathing. I now wear bra to bed to help this condition.

I hate the summer as its harder to hide my compression garments and its very uncomfortable if I do not wear them and the fluid builds up causing more stress.

Lymphoedema is an awful condition and I would not wish it on my worst enemy.

May 2013
Written evidence from the Care Quality Commission (LTC 30)

1. About the Care Quality Commission

1.1 The Care Quality Commission (CQC) was established under the Health and Social Care Act 2008 (HSCA) as the independent regulator of health and social care provision in England. CQC ensures that only providers who can meet the statutory requirements are registered to provide regulated activities in health and/or social care. Once services are registered, CQC continues to monitor and inspects them against the essential standards. It acts quickly in response to any concerns and takes swift enforcement action where services are failing people. All acute, community, mental health, ambulance, dental and adult social care providers are already registered with CQC. From 1 April 2013, all primary medical care providers, including GP practices will be registered with the CQC. We also protect the interests of vulnerable people, including those whose rights are restricted under the Mental Health Act.

2. The scope for varying the current mix of service responsibilities so that more people are treated outside hospital and the consequences of such service re-design for costs and effectiveness

2.1 We support the aspiration for people with long term conditions to be treated outside hospital. Rather than consider health and social care separately there should be a truly integrated model of care. Joint commissioning of services between health and social care via a common service specification can and should reduce overlap and duplication and go some way to integration. The main issue, however, is clarity about who is responsible for the care package each person receives at home so that they and their carers can alert someone with authority when things are not working or the package needs to be varied. This clarity can be a major benefit from jointly commissioned services with a common service specification.

2.2 Although home carers are usually a central feature of all care packages they could be funded by CCGs (NHS) or local councils and they could be contracted directly by CCGs or sub contracted by NHS from councils, depending on the outcome of the Continuing Health Care assessment. The responsibility for putting right problems in the care package can vary therefore and is often extremely opaque to users of services. Truly integrated care would not define a boundary between health and social care and would instead focus on the needs of the individual some of which will be health related and other social care related.

2.3 The issue of local authority eligibility criteria could be a factor in restricting the availability of support to some people in the earlier stages of their disease so access to preventative help (eg advice, information, assistive technology, telehealth/medicine) is important. The development of national eligibility criteria is not likely to change this much if it is set at a high level.

3. The readiness of local NHS and social care services to treat patients with long-term conditions (including multiple conditions) within the community

3.1 The NHS and social care services has insufficient capacity and focus to treat people with long terms conditions adequately. The numbers of people with long term conditions is rising due to life style issues as well as a result of people living longer. In addition the breadth of conditions that are now seen as long term conditions is also increasing. Health and social services are at risk of becoming overwhelmed by the growth in demand for care. The impact of this is increased emergency admissions into hospitals and into Emergency Departments. Primary care is not currently set up to deal with this. The focus is on treatment of illness rather than rigorous risk screening, preventions and support for self management of long terms conditions outside of hospitals.

3.2 Integrated care planning that takes a personalised approach, and looks to the longer term as health needs are likely to increase is essential. This requires good local arrangements on shared information and joint working across health and social care.

4. The practical assistance offered to commissioners to support the design of services which promote community-based care and provide for the integration of health and social care in the management of long-term conditions

4.1 We believe that there are design models available and it is important that commissioners are able to ensure providers comply with the model. We suggest that it would be most appropriate for the commissioners to focus on the provision of services from the “consumers” perspective.

5. The ability of NHS and social care providers to treat multi-morbidities and the patient as a person rather than focusing on individual conditions

5.1 More care is likely to be provided outside hospitals and care homes in the future. Primary care is best place to deal with people with multi-morbidities.

Staff can play a big role in assisting people to manage their conditions in the community and to try and improve their lifestyles where this is a factor. This requires a less task based and more personalised approach to care and support.
5.2 However there are also challenges in the community as an increasing proportion of care will be delivered through unregulated services organised by people themselves. This raises questions about assuring the safety and quality of that support and the need for sector-led standards for care that are not reliant on a statutory regulator.

5.3 The increase specialisation in hospitals leads to fragmentation of holistic care. Doctors and nurses increasingly specialise and therefore find it more of a challenge to care for elderly people with several different conditions. Staff skills will be increasingly stretched by the complex needs of increasing numbers of people with long term conditions living into old age. Links to specialist advice and support as well as continued investment in training will therefore be even more essential.

6. Obesity as a contributory factor to conditions including diabetes, heart failure and coronary heart disease and how it might be addressed

6.1 Obesity should not be an issue for the NHS to tackle. The numbers are too large. 25% of all adults in Reading for example are clinically obese (BMI 30+). The NHS can’t treat that number of new patients even if it wanted to. This has to be tackled by the government through taxation, information and education.

7. Current examples of effective integration of services across health, social care and other services which treat and manage long-term conditions

7.1 The effective management in the community of long-term conditions requires an integrated approach. NICE standards should be a starting point but relatively few cover both health and social care. A piece of work has just been completed on mental well-being for older people in care homes and ones are planned on older people with long-term conditions and on transition between health and social care. Whilst the development of more joint standards will be a big step forward, and may influence our inspection methodology, it will not transform services overnight. There needs to be a strong push from NHS England and ADASS/LGA to embed these standards and to provide the investment, planning, commissioning and training to achieve them.

8. The implications of an ageing population for the prevalence and type of long term conditions, together with evidence about the extent to which existing services will have the capacity to meet future demand

8.1 Age is a major determinant of prevalence of LTC and co-morbidity increases with years. The distribution of funding in NHS and Councils need to urgently reflect this more accurately. There are also issues of sufficiency of staff with the necessary skills to meet future demand.

8 May 2013

Written evidence from Genzyme Therapeutics Ltd (LTC 31)

1. Genzyme Therapeutics has pioneered the development and delivery of transformative therapies for patients affected by rare and debilitating diseases for over 30 years. We are focused on rare diseases and multiple sclerosis, and are dedicated to making a positive impact on the lives of the patients and families we serve.

2. We would like to draw the Committee’s attention during this inquiry to the field of rare diseases. Advances in treatments and technologies mean rare conditions that were untreatable just a few years ago—such as Lysosomal Storage Disorders (LSDs)—now fall into the Department of Health definition of “long term conditions”. There are more than 6,000 rare diseases and although individually infrequent, collectively they affect 5% of the population and are now under the control of a single direct commissioner, NHS England.

3. Due to the low prevalence, specialist clinical care for patients with LSDs is concentrated into a few tertiary centres. However, despite the complex needs of patients treatment and personal clinical care is delivered in the community through homecare companies, which liaise directly with the tertiary centres. This service model improves quality of life for patients; increases adherence to complex treatments; allows for combined physiotherapy which is an important treatment adjunct, and reduces overall costs to the NHS.

4. In considering the scope for service re-design, we believe the Committee should recognise that new treatments and technologies frequently act as the catalyst for such change. A question the Committee might like to consider is whether a formal process should exist for initiating NHS and social care service review following positive National Institute for Health and Care Excellence (NICE) technology appraisals. In this context, savings from new treatments or technologies can often accrue to social care, but upfront costs are borne by the NHS; for example in neurological conditions. Theoretically this is a technical issue to be resolved principally by NICE, but in practical terms it is a real barrier to service re-design which is created by the NHS and social care divide.

5. The use of patient treatment pathways is increasingly becoming the mechanism to fully describe the potential routes a patient takes through the care system as well as defining the impact of new treatments and technologies. Well-defined multi-stakeholder treatment pathways form the basis of many commissioning strategies and are routinely used in therapeutic areas, such as oncology. Expansion of the use of treatment
pathways would improve stakeholder input and help ensure a broader and more meaningful assessment of new treatments and technologies.

6. Neurological conditions are recognised as having high and rising rates for emergency admission and readmission, despite growing levels of resource, resulting in a previous Parliamentary Committee finding that neurological services represent poor outcomes for people with neurological conditions and poor value for money for the NHS.140 We believe that the Health Committee’s inquiry with a focus on diabetes offers an opportunity to compare and contrast with recent analysis in neurology, which was the condition upon which the 2005 the National Service Framework for Long-term Conditions was based.

8 May 2013

Written evidence from the UK Centre for Tobacco Control Studies (LTC 32)

This submission is made on behalf of the UK Centre for Tobacco Control Studies, a UKCRC Public Health Research Centre of Excellence established in 2008 and comprising a network of leading tobacco control researchers from ten UK universities. A full list of the researchers involved in the Centre, and background information on the objectives and activity of the Centre, is available at www.ukctcs.org.

Tobacco smoking is highly addictive and the largest avoidable cause of ill-health, chronic disease and premature death in the UK. The adverse effects of smoking contribute to the causation and/or exacerbation of all of the chronic conditions listed by the Select Committee in this call for evidence, with the possible exception of epilepsy. Preventing smoking is crucial to the primary and secondary prevention of these chronic conditions.

As particular examples, smoking causes over 80% of Chronic Obstructive Pulmonary Disease (COPD) and lung cancer in the UK,141 and smoking cessation is the only intervention that has a significant impact on disease progression in COPD. Around 20% of deaths from ischaemic heart disease, and 60% of those from aortic aneurysm, are attributable to smoking,142 and smoking prevention contributed more to the decline in mortality from heart disease in the UK over recent decades than almost all other interventions combined.143 Smoking among people with mental health problems accounts for the majority of reduced life expectancy of this group,144 and has been particularly neglected; in contrast to the progressive downward trend in smoking prevalence, to around 20%, in the general population, the prevalence of smoking among people with mental health problems has remained static at around 40% for the past two decades.

Any strategy to improve and prevent morbidity and mortality from long term conditions should therefore have smoking prevention and harm reduction at its core. It is of particular importance to promote all population-level preventive strategies, including the use of price, media campaigns, smoke-free policies, preventing direct and indirect advertising and promotion (for example through smoking in films marketed to children and young people) and pursuing harm reduction strategies by making alternative sources of nicotine available to the general population. At individual level, it is also essential to build smoking cessation and harm reduction into the delivery of routine care for all chronic and long-term conditions. This is especially important for those with mental health problems, for whom smoking remains culturally accepted and even facilitated by healthcare professionals, who should instead be providing treatments and support to help smokers to quit.

A recent joint report by the Royal College of Physicians and Royal College of Psychiatrists, led by UKCTCS members but with contributions from over 30 experts, drew attention to the major impact that smoking has in reducing quantity and quality of life among people with mental health problems. Key conclusions include:

- Smoking is around twice as common among people with mental disorders, and more so in those with more severe disease.
- Up to three million smokers in the UK, 30% of all smokers, have evidence of mental disorder and up to one million with longstanding disease.
- One third of all cigarettes smoked in England are smoked by people with a mental disorder.
- In contrast to the marked decline in smoking prevalence in the general population, smoking among those with mental disorder has changed little, if at all, over the past 20 years.
- Smokers with mental disorders are just as likely to want to quit than those without, but are more likely to be heavily addicted to smoking, to anticipate difficulty quitting smoking, and are historically much less likely to succeed in any quit attempt.
- Smoking cessation interventions that combine behavioural support with cessation pharmacotherapy that are effective in the general population are also likely to be effective in people with mental disorders.

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140 Public Accounts Committee—Seventy-Second Report: Services for people with neurological conditions. HC 1760. Published 13 March 2012 http://www.publications.parliament.uk/pa/cm201012/cmselect/cmpubacc/1759/175902.htm
144 Royal College of Physicians, Royal College of Psychiatrists. Smoking and mental health. London: RCP; 2013
— Smoking cessation does not exacerbate symptoms of mental disorders, and improves symptoms in the longer term.
— Smokers who do not want to quit smoking, or else feel unable to make a quit attempt, should be encouraged to cut down on smoking, and to use NRT or other nicotine-containing devices (in line with NICE tobacco harm reduction guidance) to support smoking abstinence in secondary care or other smoke-free settings, and promote the likelihood of future quit attempts.
— Smoking is however a widely accepted component of the culture of many mental health settings, making cessation more difficult for smokers.
— Smoke-free policies are a vital means of changing this culture.
— Provision of effective smoking cessation and harm reduction support for smokers is crucial in maintaining smoke-free policy.
— The NHS spends approximately £720 million per annum in primary and secondary care treating smoking-related disease in people with mental disorders.
— These costs arise from an annual estimated 2.6 million avoidable hospital admissions, 3.1 million GP consultations, and 18.8 million prescriptions.
— The majority of these service costs arise from people diagnosed with anxiety and/or depression.
— Smoking increases psychotropic drug costs in the UK by up to £40 million per annum.
— Achieving cessation in 25%, 50% and 100% of people with mental disorder would respectively result in a gain of 5.5 million, 11 million and 22 million undiscounted life years in the UK. At 3.5% discounting, the corresponding figures are 1.4, 2.7 and 5.4 million life years gained.
— Harm reduction through lifelong substitution with medicinal nicotine is highly cost-effective when compared to continuing smoking, at around £8,000 per QALY gained for lifetime nicotine patch use and £3,600 per QALY for inhalators.
— Addressing the high prevalence of smoking in people with mental disorder offers the potential to realise substantial cost savings to the NHS, as well as benefits in quantity and quality of life.

Recent draft guidance published by the National Institute for Clinical Excellence on smoking cessation in secondary care settings,145 and on tobacco harm reduction,146 provide the practical guidance necessary to ensure that smoking cessation interventions become properly integrated into NHS care delivery. We recommend that the Committee considers this guidance, and ways to ensure implementation, and particularly in relation to mental health settings, in its review of services for chronic and long-term conditions. Preventing smoking probably has more to offer in terms of preventing and ameliorating long-term conditions than any other measure.

The UKCTCS is an ESRC funded Investment. The views and statements expressed are those of the authors and do not necessarily reflect the views of the ESRC.

9 May 2013

Written evidence from British Lymphology Society (LTC 33)

British Lymphology Society (BLS) is the only UK wide organisation representing health care professionals and therapists treating Lymphoedema and associated conditions. We work very closely with the Lymphoedema Support Network which is a patient based organisation. We have seen the submission from Karen Friett, Chief Executive of the LSN and we fully endorse the information it contains about Lymphoedema and the views of the LSN as to steps which need to be taken to improve the situation. In addition BLS would make the following points:

**Avoidance of Compartmentalisation**

Lymphoedema is often associated with other co-morbidities. Patients often have to deal with the addition of diabetes cellulitis arthritis cardiovascular problems as well as obesity related issues, in the case of secondary lymphoedema patients—they may have to live with the devastating side effects of radiotherapy, or chemotherapy. These can include loss of function in the affected limb due to the damage of radiotherapy to the axilla (brachioplexus neuropathy).

In BLS’s view it is essential that a multi-disciplinary “whole person” approach is adopted. As with most long term conditions Lymphoedema does not fall neatly into a simple diagnostic or treatment methodology. We do not believe that concentrating on one type of long term condition, eg diabetes, is necessarily helpful.

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Health Committee: Evidence

**Care Quality Commission**

There are many centres who treat lymphoedema—NHS based services—hospice based services who are often only funded to see cancer patients, some services run by private practitioners, social enterprises, Any qualified providers (AQP) etc. BLS is currently in discussion with the CQC about the Registration requirements for private clinics and treatment centres providing lymphoedema services.

Whilst lymphoedema is clearly a long-term condition, the treatment needs of any one patient will vary from simple advice on the management of how to prevent the condition worsening, to the more intensive treatment of compression bandaging to reduce the size of a distorted, excess limb volume, maintaining with compression therapy, manual lymphatic drainage massage, and skin care to reduce the risk of cellulitis—and potentially surgical interventions such as liposuction. Some private service providers have been advised by CQC that since lymphoedema is a long term condition they must register.

Some private service providers have been advised by CQC that since Lymphoedema is a long term condition they must register. Whilst others have been told by CQC that the treatments they are providing are classed as complementary therapies and that they should not therefore be registered.

BLS would hope that this situation can be clarified urgently, and a consistent view provided by CQC.

It is essential that this condition is recognised and cohesive equitable services are encouraged to develop throughout the UK.

9 May 2013

**Written evidence from Sanofi Diabetes (LTC 34)**

Sanofi Diabetes works closely with healthcare professionals from across the diabetes care pathway, including diabetologists, diabetes specialist nurses and GPs with a special interest as well as allied and public health professionals. Through its support of the Diabetes Parliamentary Think Tank,147 chaired by Adrian Sanders MP, and its work with the Primary Care Diabetes Society (PCDS),148 Sanofi has developed a picture of the current management of diabetes in the NHS and the concerns of those working to deliver diabetes care. The following written submission draws on discussion and consultation with these individual groups, but is representative of Sanofi’s position only.

**Executive Summary**

— Moving more diabetes care into the community must be a priority. However, primary and community healthcare professionals must be supported with the necessary specialist input in order to improve patient outcomes.

— To ensure that local NHS and social care services are ready to treat people with diabetes in the community it is imperative that specialist knowledge is retained and developed. Access to patient outcomes and service performance data is also vital in the commissioning and provision of services in the community.

— Support is available to commissioners at a local level, however there is an acute need for national leadership in this area and we look forward to the publication of the Diabetes Action Plan; Long Term Conditions Outcomes Strategy and the Diabetes Companion Document.

— Integrated care across the diabetes care pathway is desirable. However, there are significant barriers to this becoming a reality, including the perverse incentives that are built into the current system that prevent healthcare professionals from working together.

**Response**

1. It is widely understood that keeping people with diabetes out of hospital must be a priority when designing and commissioning diabetes services. Strengthening the provision of care in the community will be integral to tackling this acknowledged over-reliance on hospital care. However, in order to guarantee the delivery of high-quality care in the community, health-care professionals working in the community will require support from specialists. In July 2012, the Keeping People with Diabetes out of Hospital (KPDOH) Expert Working Group recommended that GPs should have regular contact with specialists in a community setting in order to review more complex cases; prevent unnecessary referrals into secondary care; and enable GPs to develop disease

147 The Diabetes Think Tank is a parliamentary forum chaired by Adrian Sanders MP. The Think Tank has been meeting in Westminster since 2008 and is designed to bring together policy makers, patient group representatives and clinical diabetes specialists from across the diabetes care pathway to discuss and propose solutions to current challenges faced by the diabetes community. Sanofi supports the Think Tank by the way of a grant and has no editorial control over its recommendations.

148 In 2011, the Primary Care Diabetes Society (PCDS) convened the Keeping People with Diabetes out of Hospital (KPDOH) Expert Working Group. This group produced a policy report on hospital avoidance strategies in diabetes available here: http://www.pcdsociety.org/media/Keeping_People_with_Diabetes_out_of_Hospital_-_A_report_by_the_Primary_Care_Diabetes_Society.pdf Sanofi supported PCDS with the KPDOH project by the way of a grant and had no editorial control over its recommendations.
specific knowledge. This may not require extensive service re-design, but simply take the form of a regular multi-disciplinary team meeting held in the GP practice.

Local professional networks are also valuable in engendering the flow of information, skills and knowledge across the pathway. At a time when professional education budgets are severely restricted, professional clinical networks can play a significant role in improving levels of specialist knowledge in the community.

2. There are two issues to be addressed when assessing the “readiness” of local health and social care systems to treat and support people with long-term conditions. Firstly the workforce and level of specialist expertise in the system has a significant impact on “readiness” and indeed the responsiveness of the care system. The wholesale re-organisation of the NHS and the move towards a more “generic” approach to system structures (preventing mortality; chronic disease management; recovery from episodes of ill health; patient safety; and quality) have prompted debate on the “dilution” of disease-specific skills in the commissioning and delivery of diabetes services in both primary and secondary care. The role of Diabetes Specialist Nurses (DSNs) has been the headline discussion topic at two Diabetes Think Tank meetings, and the retention and development of this sector of the diabetes clinical profession has pervaded all discussions. Concerns have been raised that as financial constraints take hold, investment in training, recruiting and retaining DSNs has been de-prioritised. Evidence shows that DSNs have a significant impact on the quality of patient outcomes and if the strength of the workforce is corroded, patients will be negatively impacted.

Secondly it is vital that commissioners and providers have access to data relating to individual patients, local health outcomes and service performance from across the pathway, both nationally and from within their own locality. The KPDOH Expert Working Group recommended that strategies for sharing patient information should be explored, specifically taking on the challenge of patient consent. Patients expect healthcare professionals to have all of the information necessary to make informed decisions about their care, yet barriers remain that prevent the necessary transparency.

3. The Diabetes Action Plan; Long Term Conditions Outcomes Strategy; and the Diabetes Companion Document have all been delayed and it is our understanding that they will now be published by NHS England, and not the Department of Health. A timeline for the publication of these long anticipated documents is still not clear. At the most recent meeting of the Diabetes Think Tank (1 May 2013) it was clear that without a national strategy diabetes clinical community is in a state of flux. Whilst it is understood that NHS England are looking for change to be driven locally, there is a desire for national leadership to guide this change at a service-specific level.

We welcome the publication of Best practice for commissioning diabetes services: An integrated care framework, a document co-produced by NHS Diabetes, the Department of Health and leading patient and professional associations.

4. Integrated care is widely acknowledged as a desirable outcome in the re-organisation of the NHS and would enhance the quality of service received by people with multiple chronic diseases. However, members of the Diabetes Think Tank strongly believe that the present payment system poses a major barrier to achieving it. In particular it was noted that the purchaser-provider split at the centre of the health system and the resulting competition between healthcare providers fails to adequately incentivise healthcare professionals to work together to provide joined-up care for people with diabetes.

It was further observed that the present system of tariff payments provides secondary care diabetes specialists with a perverse incentive, encouraging them to treat simpler cases to maximise profit for their Trust, rather than focus on the more complex patients who require more attention and therefore more resource.

The Think Tank agreed that in order to enable greater integration of care, the financial model needs to match the model of care that it is meant to deliver. It was suggested that if healthcare professionals were placed within an incentive system which encouraged joint working, the service would transform itself accordingly. Furthermore, there needs to be greater clarity as to the exact size of local diabetes budgets, and who is responsible for the allocation of funds across the entire integrated pathway.

In addition to redressing the balance of incentives, it is imperative that Health and Wellbeing Boards place emphasis on the importance of integrated diabetes service provision in their Joint Strategic Needs Assessments (JSNAs).

There are a number of integrated diabetes care models working successfully in the NHS including models in Derby, Portsmouth and North West London. However, it is important to note that there is no “one-size fits all” model which commissioners should seek to deliver in every locality. The availability of a choice of models will be greatly desirable in providing a service tailored to the specific needs of the local health economy.

5. The KPDOH Expert Working Group identified a number of integrated care models in its report. These models particularly focused on reducing avoidable hospital admissions amongst people with diabetes.

Full details of these case studies are available here (pp.23—39): http://www.pcdsociety.org/media/Keeping_People_with_Diabetes_out_of_Hospital_-_A_report_by_the_Primary_Care_Diabetes_Society.pdf

6. Research by the Institute of Diabetes for Older People (IDOP) shows that the median age of inpatients in more than 200 Acute NHS Trusts is 75 years and the majority have been admitted as an emergency. This report
also found that factors which increase the likelihood of hospital admission of older people included care home residency, mis-management of medication and carer fatigue, among others. Diabetes UK (2010) found that six out of ten care homes in England which have residents with diabetes, fail to provide any training to their staff about the condition. Diabetes UK also found that only 23% of care homes screen their residents for the condition on admission. The report concluded that this missed screening could mean that as many as 13,500 care home residents could have undiagnosed Type 2 diabetes and could be at increased risk of developing complications. All diabetes complications (excluding Diabetic Ketoacidosis) become more likely with increasing age and duration of diabetes and it is vital that this group have their condition closely monitored. The KDPOH Expert Working Group noted that diabetes care delivered in care homes is often not appropriate and that support needs to be available to care workers to ensure that specialist diabetes care is available where necessary.

7. It is known that people with severe and enduring mental health problems have a greater risk of long-term physical health problems, including diabetes, which can lead to increased hospitalisation and early mortality.

Birmingham and Solihull Mental Health Foundation Trust has developed a model for managing and treating people with diabetes in their care. A diabetes lead has been appointed within the Trust to support this vulnerable group of patients. Early evidence demonstrates a positive impact on patient outcomes. More details of this model are available in the KPDHO Expert Working Group’s report.

9 May 2013

Written evidence from the Association of British Clinical Diabetologists (LTC 35)

SERVICES PROVIDED FOR PATIENTS WITH DIABETES

SUMMARY

— This document provides evidence from the Association of British Clinical Diabetologists (ABCD), commenting on long term conditions from the viewpoint of people with diabetes.
— Diabetes care in the UK is principally delivered by primary care teams, usually by the Practice Nurse.
— Incentives and penalties limit contact of people with diabetes with the specialist teams until late in their disease process.
— There is an urgent need for pilot work which would explore the best means and value of true integration between the specialty teams and primary care.
— The team structure required to treat people with multiple morbidities in the community does not currently exist in the NHS.
— There is a considerable amount of published information and advice for those who commission services for people with diabetes and this should be incorporated in service specifications.
— The care pathways for people with diabetes centres entirely upon the general practitioner. The resulting pathway, while notionally attractive, remains difficult for people with diabetes and hampers integrated care.
— The concept of an integrated care organisation for people with diabetes should be explored.

1. The scope for varying the current mix of service responsibilities so that more people with diabetes are treated outside hospital and the consequences of such service re-design for costs and effectiveness.

(a) Since the 1990s there has been a drift away from providing routine diabetes care within the hospital sector. This has been driven by a number of changes, most significantly the willingness of specialist diabetes teams to work outside the hospital setting. More recently, diabetes figured significantly in the QOF payment incentives. This, more than anything, persuaded primary care that they should manage diabetes in-house to ensure that their income was maximised. The Payment by Results system put a tariff on all referrals to specialist care which has also limited the flow of patients to the hospital sector. Unfortunately these changes have come about due to financial incentives and penalties, but any financial gains have not been ploughed back into diabetes care. The bill for diabetes care continues to grow, but this is largely made up of increases in the medicines budget with increases in the medical and social costs due to disability.

(b) The end result has been that the percentage of patients seen in the hospital sector is already limited. This would probably range from a figure of 10–30% of patients being seen in a hospital setting, although that figure will vary according to local arrangements, and will usually be at the lower end of that range. People with diabetes now tend to be referred later in their disease process at which
point they already have diabetes complications which may not be amenable to treatment at that stage.\textsuperscript{152}

(c) It is argued, therefore, that the UK has a practice nurse delivered diabetes system. With a few notable exceptions, it is the practice nurses who will deliver routine diabetes care. There are many reasons why this is inappropriate. However, the main problem is that although the practices nurses are well motivated and dedicated, they do not have the appropriate training for this role given the various other calls upon their time and generally work in isolation.

d) To allow diabetes care to be adequately delivered in primary care there will need to be a considerable expansion in staffing in that sector to allow for adequate care planning for the 5–6% of patients with diabetes. At the same time there is a requirement to design and commission an interface between the specialist team and primary care to allow the two sectors to work together. Diabetes specialist teams remain keen to work across the interface but the hardening of the organisational and financial barriers in the modern NHS makes this increasingly difficult.

2. The readiness of local NHS and social care services to treat with long term conditions (including multiple conditions) within the community.

(a) The NHS is not optimally structured to treat patients with multiple morbidities in the community. Notionally, this would be the role of the GP, but the concept is now outdated due to increasing complexity of treatment and the increasingly pressurised role of primary care.

(b) At its simplest, the healthcare system can be divided into primary care, secondary care and social services. In recent years, the concept of multiple providers has fragmented this system further by introducing new organisations which duplicate activity rather than innovate. Communication between organisations is poor and budgetary allocations harden divisions.

(c) To be able to manage complex conditions in the community, there needs to be a team of healthcare professionals who can work within a common organisation which bridges all of the current functions. This team would include a senior doctor. In the context of diabetes, this would be a Consultant in diabetes given that the specialty remains wedded to the concept of general medicine rather than single organ systems. Patients with diabetes commonly have multiple morbidities, most commonly ischaemic heart disease, heart failure, kidney failure, peripheral vascular disease, advanced eye disease and amputation. As a result of these co-morbidities, they are often poorly mobile with high social care needs. The wider team therefore needs connections with social services and the therapies on the one hand, but as this patient group is extremely vulnerable medically, there also needs to be a bridge with the acute hospital to organise complex investigations and to provide in-reach in the event that the patient is transported to hospital.

(d) Ideally this team would operate within the same organisation, with shared management, a single budget and shared IT systems. Alternatively it would need to be set up as a virtual organisation with cooperation between the different providers.

3. The practical assistance offered to commissioners to support the design of services which promote community-based care and provide for the integration of health and social care in the management of long-term conditions:

(a) The Association of British Clinical Diabetologists (ABCD), as the national association representing Consultants in diabetes within the UK, has had input into a variety of documents to guide those who commission services for people with diabetes.\textsuperscript{153} The major message has been integration of care. Patients with diabetes require access to multiple services at different times in their lives, ranging from a diabetes pregnancy clinic to a wheelchair service to social services. The advice provided outlines practical steps to integration of care.

4. The ability of NHS and social care providers to treat multi-morbidities and the patient as a person rather than focusing on individual conditions:

(a) While GPs may remain as generalists, specialist care is increasingly organ or system specific. The practical result of this is that an individual with multiple morbidities, using their GP as a central point of referral, is sent to multiple appointments and locations and back to their GP with little communication between each of the services. The care pathway therefore resembles a cricket batsman’s stroke pattern rather than a smooth continuum. While Consultants in diabetes maintain one of the few specialities with an ongoing commitment to generalism rather than a single organ system, their work pattern is constrained by the current geography of the healthcare system.

(b) From the perspective of an individual with diabetes, the care pathway must be made simpler.\textsuperscript{154} They wish to be referred to a single point of reference where all of their various problems can be managed. The NHS is currently not set up to do this. The system needs to be changed towards a model of integrated care organisations with a team which operates freely between primary care, social services and secondary care.


\textsuperscript{153} http://www.diabetes.nhs.uk/commissioning/

\textsuperscript{154} http://www.policexchange.org.uk/images/publications/all%20together%20now.pdf
5. Current examples of effective integration of services across health, social care and other services which treat and manage long-term conditions:

(a) Examples of integration of care within diabetes extend only to limited integration of medical services. There have, for example, been social enterprises set up between primary and secondary care to manage diabetes. In other examples, secondary care teams have gained the contract for community care of diabetes by forming separate companies outside the acute Trust. Such examples do not extend to true integration of care as an integrated care organisation.

Current examples of integration of care include:

— A social enterprise for diabetes care in Derby.
— Consultants in diabetes bidding for the community diabetes service in Portsmouth and running this as a limited liability company in conjunction with a community provider.
— A joint initiative between primary and secondary care in Hull to improve diabetes screening with education sessions for those newly diagnosed.155
— A joint initiative to improve diabetes care through care planning in North West London.156

9 May 2013

Written evidence from Crohn’s and Colitis UK (LTC 36)

1. INTRODUCTION

1.1 About 250,000 people in the UK have Crohn’s Disease or Ulcerative Colitis, collectively known as Inflammatory Bowel Disease (IBD). However, awareness and understanding of these conditions remain very low.

1.2 These are lifelong conditions that most commonly diagnosed between 10 and 40. In IBD, the intestines become swollen, inflamed and ulcerated. Symptoms include frequent diarrhoea (sometimes with blood and mucus), acute abdominal pain, tenesmus (the constant urge to have a bowel movement), weight loss, and profound fatigue. Symptoms vary in severity from person to person and flare up or improve unpredictably. IBD therefore fulfils the Department of Health’s definition of a long-term condition.

1.3 The majority of IBD Patients are managed as outpatients by specialist IBD Teams based in secondary care. The traditional approach has been to keep these patients on regular clinic follow-up to monitor their well-being, and this has in many hospitals been supplemented by a specialist nurse-led helpline to provide support and triage patients if their condition flares.

1.4 Annual reviews for people with IBD are vital once people are discharged to primary care as these are not systematically carried out and patients can be lost to follow-up. This could be addressed by a comprehensive registry of IBD patients, which can be accessed by GPs.

1.5 We welcome the fact that people with IBD want to be treated at home, but this needs to be provided safely.

1.6 The total cost of IBD to the NHS has been estimated at £720 million, based on an average cost of £3,000 per patient per year with up to half of total costs attributed to relapsing patients.157

1.7 We welcome Government efforts to increase the integration of care, which supports self-management for people with IBD whose conditions are stable.

1.8 However, there are a number of organisational and institutional barriers to achieving this, including:

— Knowledge and understanding of IBD and its treatment in primary care.
— The Payment By Results system, which incentivises hospital attendances.
— Lack of a national register of IBD patients.

2. THE SCOPE FOR VARYING THE CURRENT MIX OF SERVICE RESPONSIBILITIES SO THAT MORE PEOPLE ARE TREATED OUTSIDE HOSPITAL AND THE CONSEQUENCES OF SUCH SERVICE RE-DESIGN FOR COSTS AND EFFECTIVENESS

2.1 Increasingly hospitals have begun to introduce nurse-led telephone or virtual clinics to reduce the numbers of routine clinic appointments for essentially “well” patients. Supported self-management has also been tried in a formal controlled trial and found to be safe and to reduce hospital and GP appointments. These approaches are encouraged in the UK IBD Standards, which aim to ensure that IBD patients receive consistent,
high-quality care. The IBD Standards were developed by Crohn’s and Colitis UK and other professional organisations, and launched in 2009.

2.2 IBD nurse specialists are highly valued by people with IBD, as members of Crohn’s and Colitis UK explain—

“I prefer to self-manage my condition and only refer to the IBD nurse when forced to due to a flare-up, or when I need to turn up for an annual check up in the IBD Clinic Oxford. Supported self-management would surely free up time in the hospitals and give sufferers some degree of confidence to self-manage—with the knowledge of a sound back-up service with the IBD nurse.”

“I have had flare-ups whilst on holiday abroad and I have telephoned the IBD nurse and we have had an email correspondence which was been helpful and reassuring. This email/phone connection with an IBD nurse and the service they give both initially, and when needing advice, is imperative. It is valuable and necessary for patients and it would also alleviate any pressure on doctors/consultants.”

2.3 However, the scope for varying the current mix of services is limited by key structural and organisational barriers.

2.4 The current Payment by Results (PbR) system means that commissioners pay healthcare providers for each patient seen or treated. This means that there is a correlation between procedural activity and income to hospital trusts.

2.5 As it is only outpatient clinics and formal telephone clinics for which tariff payments are available, there is no incentive for any activity which avoids hospital attendances, such as an IBD nurse helpline, though avoiding attendance or admission is clearly in the patients’ best interests and saves NHS resources. As a result there is a constant battle to justify and protect the role of the IBD Specialist Nurse which is central to good care for Inflammatory Bowel Disease.

2.6 Crohn’s and Colitis UK is calling for a “year-of-IBD-care” tariff, which would mean that funding follows the patient between services and is not organised around specific interventions. It reflects a way of commissioning a year’s worth of care at a time, rather than paying for individual interventions. This is a model that could help improve long-term conditions management in a range of long-term conditions.

2.7 According to a recent report by the Royal College of Physicians into the locus of treatment for people with IBD, “Almost all GP’s [sic] indicated having some level of confidence in recognising the key symptoms of IBD in their patients with only 9.1% indicating that they were “not confident” in dealing with flare-ups. There does however, seem to be a wide range in the treatments given and this may depend upon whether GPs try to contact specialists for advice and indeed if they do, who it is that they choose to contact.”

2.8 The report revealed that GPs were, in many cases, unclear about whom they should contact in secondary care to discuss a patient, and that they found it difficult to get patients seen within seven days, despite hospitals’ insistences that pathways for rapid access were available.

2.9 Crohn’s and Colitis UK has also received anecdotal evidence from queries submitted to our Information Service that GPs sometimes question treatments for IBD, and appear unaware of the debilitating psychological and social impacts that the condition can present.

2.10 Members of Crohn’s and Colitis UK have reported variable knowledge of IBD among GPs:

“[My] GPs don’t seem to know what to do to manage the condition. Consultant appointments tend to be very quick, and I don’t believe that they are at all adequate from a patient perspective. This is where a specialist IBD nurse would be very useful—they are often more empathic than consultants, for a start.”

“Though my GP is always very supportive and does whatever he can to try to manage my care when there’s a problem and I’m not able to be seen by a specialist, once he’s referred me to a consultant/specialist nurse/dietician, it shouldn’t really be his [the GP’s] job to change my treatment. Otherwise, why send me to an “expert”?”

2.11 Taken together, this suggests that there is potential for IBD patients to be managed effectively in primary care or through supported self management if their condition is stable, but this is limited by the above.

3. The Readiness of Local NHS and Social Care Services to Treat Patients with Long-Term Conditions (including multiple conditions) within the Community

3.1 There seems to be little recognition that the current procedural tariffs are a major barrier to the development of more innovative and patient-centred care for IBD. Unless there are identifiable funds that can be allocated to enable an integrated care pathway of the ongoing management of mild to moderate stable IBD, it will be very difficult to secure the funding commitment to redesign and modernise services.

3.2 There have been numbers of innovative approaches to providing cost-effective patient centred outpatient care in IBD, but there has not so far been a systematic application of these to the system of care in one Board or CCG to demonstrate the benefit of delivering a fully-integrated IBD Service combining some of these developments. At present commissioning bodies have not seen the potential for this and may well consider IBD not significant enough as a condition to initiate such a project.

4. The Interaction between Mental Health Conditions and Long-Term Physical Health Conditions

4.1. IBD specialists often find it very difficult to obtain professional psychological support for patients. We feel that this is an example of a service that is probably needed by a proportion of patients for all long-term conditions. The NHS Commissioning Board should encourage commissioners to explore the provision of a Long-term Conditions Hub to provide expertise across conditions which would be harder to justify on a single condition basis.

4.2. There is also an issue around the provision of support for lifestyle issues and the management of pain and fatigue which are poorly managed in secondary care. Integration of care could allow management of these symptoms in local settings. This model could also be beneficial for people with other long-term conditions.

About Crohn’s and Colitis UK

Crohn’s and Colitis UK is the major charity offering information and support to anyone in the UK affected by these conditions. Established in 1979 as a partnership between patients, their families and the health professionals caring for them, the charity’s services include four information and support services, a website, a wide range of accredited information sheets and booklets and a nationwide network of locally based Groups. The charity also raises awareness of these little-known conditions, campaigns for improved health and social provision for patients, and funds vital research. Crohn’s and Colitis UK is the working name for the National Association for Colitis and Crohn’s Disease and currently has nearly 31,000 members across the UK.

9 May 2013

Written evidence from Scope (LTC 37)

ABOUT SCOPE

We all want to live in a world of opportunity—to be able to live our own life, play our part and be valued for the person we are. At Scope we’re passionate about possibility. It inspires us every day and means we never set limits on people’s potential.

We work with disabled people and their families at every stage of their lives. From offering day to day support and information, to challenging assumptions about disability and influencing decision makers—everything we do is about creating real and lasting change.

We believe that a world where all disabled people have the same opportunities as everyone else would be a pretty incredible place for all of us. Together we can make it happen.

Scope welcomes the opportunity to submit evidence to this Inquiry.

The practical assistance offered to commissioners to support the design of services which promote community-based care and provide for the integration of health and social care in the management of long-term conditions

Funding and long-term investment

1. Funding and long-term investment in social care is critical to supporting commissioners to commission integrated, cost-effective services in the management of long-term conditions.

2. Whilst Scope strongly supports the Government’s aim to bring about closer working and cooperation between health and social care, (particularly the Clinical Commissioning Groups and local councils respectively), financial pressures and different funding streams mitigate against this. In these times of austerity, both NHS and council partners are even more protective of their budgets and there is no incentive to contribute to a person’s care when the savings may accrue to another area.

3. Due to chronic underfunding of social care, the eligibility criteria for receiving local authority funded services are becoming ever tighter, either at the “substantial” or “critical” level of FACS.159 This means that people with long-term conditions living in the community will not be able to access help before they reach crisis point. At this stage, it is likely that their physical and mental health needs will have intensified, requiring them to draw more heavily on local health, as well as social care, services.

159 Currently, eligibility for support is assessed against the Prioritising Need framework, also referred to the Fair Access to Care Services criteria. FACS is based on the impact faced by an individual if issues relating to their independence are not addressed and is defined across four bands; “Low”, “Moderate”, “Substantial” and “Critical.” http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113154
4. The Other Care Crisis, a joint report from Scope and four other disability charities using research commissioned from the Personal Social Services Research Unit at the London School of Economics, found that over 105,000 disabled people of working age risk losing out on vital care and support. The report recommended setting the proposed national eligibility threshold at moderate FACS or equivalent. It estimated that:

- The total cost of setting the eligibility threshold at “moderate” for working age disabled people will be £1.2 billion or 0.17% of public expenditure in addition to current spending on social care.
- For older people, the net cost of a “moderate” level threshold will be £1.6 billion or 0.23% of public expenditure.
- Providing care to all people (both disabled adults and older people) with “moderate” needs and above would cost £2.8 billion on top of the planned reforms, which amounts to just 0.4% of public expenditure.

Data and information sharing

5. Up to date data about local populations is key to better planning and commissioning of services. As the recently published guidance on Joint Strategic Needs Assessments and Health and Wellbeing Strategies states, the Health and Social Care Act “supports the principle of local clinical leadership and democratically elected leaders working together to deliver the best health and care services based on the best evidence of local needs.” However, Scope fears that neither Clinical Commissioning Groups (CCGs) nor Health and Wellbeing Boards (HWBs) currently have sufficient or comprehensive data to enable commissioners to make fully informed decisions.

6. Providers from all sectors make a significant contribution to the planning, delivery and improvement in care and support services. They hold valuable information about the individuals in their care and are experienced in developing new models of service delivery and so must be included in the list of partners which local authorities are required to co-operate with. However, in our experience, information sharing between local authorities and by the local authority with partners from the voluntary sector is often poor.

Recommendations

7. Increased investment in social care is essential to enable commissioners to commission integrated cost effective services in the management of long-term conditions.

8. The NHS Commissioning Board should promote:
   - greater use of pooled budgets between health and social care; and
   - a standard framework for the collection of data which informs JSNAs, which is common to CCGs and HWBs across the country.

9. Provisions in the forthcoming Care Bill should:
   - require a local authority to collect and refresh a minimum data set about the current and future needs of their local populations as part of their market shaping duties.

9 May 2013

Written evidence from Julie Hinks (LTC 38)

At the age of 41 I had breast cancer in 2006 and consequently had to have a mastectomy. I had reconstruction at the time of my surgery which unfortunately was unsuccessful so had to have further corrective reconstruction in 2010. As a result of my initial surgery I developed lymphoedema in my left arm. A part from regular measurements and supply of compression sleeves there is no MLD (Manual Lymphatic Drainage) available in our area.

I have been paying an excellent private MLD practitioner on a regular basis for the past five years. This treatment has vastly improved and managed my condition and this is going to be on going for the rest of my life.

I know it is the case with a lot of ladies that I have come into contact with that have developed Lymphoedema following surgery that it is just treated as unfortunate and something we have to just deal with. I know financially the NHS is extremely stretched but as more an ladies are now ending up with this lifelong disability it seems very sad that his problem is not being totally understood and treated as the disability it is. I have to be constantly aware of what I do in my day to day living and am not able to do a lot of activities and general work that I used to be able to do.

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160 Scope, Leonard Cheshire Disability, Sense, Mencap & The National Autistic Society (2013) The Other Care Crisis

I hope my account of my situation helps in maybe looking into this problem that affects so many people.

9 May 2013

Written evidence from the Royal National Institute of Blind People (LTC 39)

ABOUT US

1. As the largest organisation of blind and partially sighted people in the UK, the Royal National Institute of Blind People (RNIB) is pleased to have the opportunity to respond to this inquiry.

1.1 We are a membership organisation with over 10,000 members who are blind, partially sighted or the friends and family of people with sight loss. 80% of our Trustees and Assembly Members are blind or partially sighted. We encourage members to be involved in our work and regularly consult with them on government policy and their ideas for change.

1.2 As a campaigning organisation of blind and partially sighted people, we fight for the rights of people with sight loss in each of the UK’s four countries. Our priorities are to:
   — Stop people losing their sight unnecessarily.
   — Support independent living for blind and partially sighted people.
   — Create a society that is inclusive of blind and partially sighted people’s interests and needs.

1.3 We also provide expert knowledge to business and the public sector through consultancy on improving the accessibility of the built environment, technology, products and services.

MAIN POINTS

2. Glaucoma and diabetic eye disease should be recognised in any consideration of long term conditions.

3. The aging population has massive implications for the number of people with the sight threatening conditions glaucoma and diabetic eye disease. Already eye clinics are struggling to keep up with demand and this issue needs addressing as demand increases.

4. Sight loss has a massive compound impact on a person’s health in a number of different ways. These can be managed with therapies or health service design: as such sight loss should be considered for its impact as a co-morbidity for people with long term conditions.

5. Sight loss affects around two million people and it has, in itself, a massive impact on health and wellbeing, on a daily basis. As such sight loss, whether treatable with medicines or not, should be considered in itself to be a long term condition.

SPECIFIC POINTS

6. The eye diseases glaucoma and diabetic retinopathy must be recognised as serious long term conditions.

7. Glaucoma:

7.1 Prevalence: In 2010 there were estimated to be 266,000 people living with detected glaucoma in the UK, and an additional 191,000 people were living with undetected Glaucoma.

7.2 Current management: Sight loss from glaucoma is largely avoidable with regular treatment: life-long daily eye drops and routine check-ups with an ophthalmologist to check that treatment is working is the usual management routine.

7.3 Risk factors: Several things increase your risk of developing the most common type primary open angle glaucoma (POAG): age—POAG becomes much more common as people get older. It is uncommon below the age of 40 but this type of glaucoma affects one% of people aged over 40. About five% of people over the age of 65 have primary open angle glaucoma. Race: if you are of African origin you are more at risk of POAG. It is also more likely to develop at an earlier age and be more severe. Having a family with glaucoma, short sight or diabetes all increase your chances of developing glaucoma.162

7.4 Current management issues: Late diagnosis of glaucoma is a particular problem and is often due to the fact that initial sight loss from glaucoma is generally undetected by patients unless it is well advanced. Glaucoma is nevertheless easily detected by an eye test, even before it causes sight loss, which should be taken every two years.

7.5 People also “fall through the net” by having delayed or cancelled check-up appointments and lose sight as a result. We have found that well over half of eye clinics do not keep a track of how many glaucoma appointments are delayed or cancelled.163

162 RNIB and RCOpth 2010 “Understanding Glaucoma” RNIB and RCOpth: http://www.rnib.org.uk/eyehealth/eyeconditions/eyeconditionsdn/Pages/glaucoma.aspx
163 RNIB, (2012) “Save Our Sight” RNIB
7.6 Patients can also struggle to take their medication daily—sometimes they do not fully understand the need for medication or they may simply forget.

7.7 Patients may struggle to physically put the medication drops in, for example if they have arthritis. There is not always adequate care to help administer eye drops if patients struggle.

7.8 Capacity problems in eye clinics are also a massive issue (see below point on capacity 9.3)

7.9 Care in the community: use of community initiatives: capacity in eye clinics is reaching its limit.\textsuperscript{164} Glaucoma “shared care” in the community has been trialled in a number of areas and shows that by monitoring glaucoma patients in the community instead of in a hospital setting it is possible to reduce capacity problems in eye hospitals. The College of Optometrists and The Royal College of Ophthalmologists have produced a review of these initiatives.\textsuperscript{165}

8. Diabetic Retinopathy (DR):

8.1 Prevalence: between 5 and 10% of all diabetics develop the sight threatening eye disease proliferative retinopathy. It is more common in people with type 1 diabetes than type 2, 60% of type 1 diabetics show some signs of proliferative disease after having diabetes for 30 years.

8.2 Current management: patients are offered laser treatment for retinopathy and anti-VEGF injections for diabetic macular oedema. In addition life-long control of blood-glucose level decreases the chances of developing retinopathy.

8.3 Risk factors: the risk of developing diabetic retinopathy can be lowered with good blood sugar control. If detected early, with retinal screening, early access treatment can help save sight. Obesity should be recognised as having a link with sight loss. Obesity is linked to diabetes which can cause sight loss (see above). Obesity is also a factor in AMD and cataracts.\textsuperscript{166}

8.4 Management issues: variation in screening: In 2011–12, the screening service identified 2.59 million people with diabetes. 98.6% of these were offered screening, but only 80.9% of those offered were screened. The uptake variation in England varies from 95% (highest PCT) to 66.7% (lowest PCT).\textsuperscript{167}

8.5 Lack of patient centred care: Patients with diabetes struggle to balance their many health care appointments with work and family/childcare commitments and inevitably some appointments are missed. Health services should be designed around the patient so someone with diabetes can have their diabetic retinal screening, full eye examination and foot check all in one go—rather than three different appointments and visits to the hospital/optometry.\textsuperscript{168}

8.6 Capacity problems in eye clinics are also a massive issue (see below point on capacity 9.3)

9. The prevalence of glaucoma and diabetic eye disease is affected by an ageing population and affects a growing number of people.

9.1 From 2010 to 2020, the number of people with diabetic eye disease and glaucoma is set to rise by up to 25%.\textsuperscript{169}

9.2 There is increasing evidence that demand is not currently being met in eye clinics which means people are losing their sight unnecessarily.\textsuperscript{170} Problems will only increase unless the issue is tackled now. More eye conditions than ever are now treatable and this will increase in the future—coupled with the demands of an aging population eye care capacity must be addressed.\textsuperscript{171}

10. Current examples of effective integration of services:

10.1 Eye Clinic Liaison Officers (ECLOs) are employees in an eye ward who offer a bridge between health and social care services to people with conditions such as glaucoma or diabetic eye disease. They can: offer information about how to manage the eye conditions, play a role in providing accessible information, signpost patients to appropriate rehabilitation services if they lose a significant amount of sight, talk through treatment options or diagnosis information and prevent patients “falling between the gaps” in the system if hospital appointments are cancelled.\textsuperscript{172} Secondary care doctors are not equipped with the time or training to confront mental health issues that arise as

\textsuperscript{164} Anecdotally this is very much in evidence, see also the Macular “wAMD clinic survey”

\textsuperscript{165} College of Optometrists and Royal College of Ophthalmologists (2013) “Commissioning better eye care” pp 7–8.

\textsuperscript{166} RNIB and Royal College of Ophthalmologists, 2010 “Understanding Cataracts” and “Understanding AMD” RNIB.


\textsuperscript{168} Carol Hayden et al (2012) “The barriers and enablers that affect access to primary and secondary eye care across the UK” RNIB and Shared Intelligence


\textsuperscript{170} A survey conducted by the Macular Society for the Vision 2020UK group last year suggested that 80 per cent of eye clinics fail to meet the four weekly follow up appointment times needed the treatment of wet macular denegation: See also RNIB (2012) “Save Our Sight” which reveals that many glaucoma clinics have significant delays in follow up appointments.

\textsuperscript{171} This year alone diabetic oedema and retinal vein occlusion are approved by NICE as able to be treated with anti-VEGF agents. The Macular Interest Group, of which RNIB is a member, estimates that demand for anti-VEGF is likely to increase at least 50 per cent and up to 70 or 80 per cent in some areas.

\textsuperscript{172} For an evaluation of the current services see Subramanian, Conway and Gillespie-Gallery (2011) “The role of the eye clinic liaison officer”: RNIB.
a consequence of their patient’s ill health, but ECLOs are able to discuss wellbeing with patients. RNIB recently published a report outlining the critical role that ECLOs play in patient care and this can be accessed at: http://bit.ly/XcLm8t

10.2 Linking low vision services (commonly funded by local authorities and found in a hospital environment) provide aids and rehab services to people with sight loss. Linking these services with counselling services has a significant impact on patient’s independence, physiological outcomes, confidence and ability to socialise.

11. The interaction between mental health conditions and long-term physical health conditions.

11.1 People facing a disabling illness are much more likely to face mental health problems as well—especially those with sight loss. Yet the majority of people who are registered blind are told there is “nothing more that can be done”, discharged from the hospital and left cope on their own. Linking low vision services (which provide aids and rehab services) with counselling services has a significant impact on patient’s independence, physiological outcomes, confidence and ability to socialise.

11.2 Linking services that already exist is a cost effective way to improve outcomes.

12. On the ability of NHS and social care providers to treat multi-morbidities and the patient as a person rather than focusing on individual conditions.

12.1 Older people are the main users of the NHS and are much more likely than the general population to have sight loss in addition to another condition which will affect its management. Sight loss must be considered in the planning of NHS services if patients are to receive care centred around them. There are around two million people in the UK living with sight loss and that number is set to reach four million by 2050. Sight loss predominantly affects older people: one in 30 of the general population are living with sight loss—that figure rises to one in five people aged 75 and one in two people aged 90 and over are living with sight loss.

13. Sight loss has a massive impact on a person’s ability to manage a long term condition and itself has a massive impact on health and wellbeing in general. As such, sight loss itself should be considered in light of its impact as a co-morbidity which affects long term conditions.

13.1 As outlined below, people with sight loss who use the NHS face multiple barriers in the current system as sight loss is often not considered or catered to even inside the immediate eye care setting:

— Information on healthcare and appointments is not available in an accessible format such as braille, large print or email.

— Food and drink is frequently left on bedside tables without the person being told it is there or where it is.

— Staff are unable or unwilling to offer basic guiding, and

— Patents are not explained how to undertake medical examinations, such as a blood test, in a way that is appropriate for someone with sight loss.

13.2 People who have stroke, dementia or a learning disability can often have sight loss which is undiagnosed—which adds further difficulties to their treatment.

13.3 People who have a stroke are more likely to have sight loss. However, Rowe, a leading researcher in the field, noted that currently: Often staff on stroke teams do not refer patients for...
vision assessment because of a common misperception that little can be done to treat visual impairment following stroke.\(^{180}\)

People with learning disabilities are ten times more likely to have eye problems than the general population but are less likely to receive timely and appropriate care.\(^ {151}\)

13.3.3 People with dementia and sight loss face everyday living problems caused by sight loss which are masked by and wrongly attributed to dementia. People with dementia can also develop vision problems as a result of their dementia. 750,000 people have dementia in the UK, most of whom are over 65 and around one in seven of the over 65s is living with significant sight loss. By the age of 75 at least 2.5% of people will have both conditions.\(^ {182}\)

13.3.4 Patient convenience is patchy and jeopardises care: see points 8.5.

14. Sight loss should be considered as a long term condition in itself due to its impact on health and wellbeing.

About two million people have sight loss in the UK. People can develop sight loss for a number of reasons. Wet Age related macular degeneration affects central vision and about 40,000 people per year develop wet AMD.\(^ {183}\) In addition, a further 500,000 people are living with dry type untreatable AMD. This has a massive impact on a person’s general health and wellbeing, for example people with sight loss:

- are nearly 40% more likely to have experienced difficulty accessing NHS services in the last 12 months than people with no disability.\(^ {184}\)
- disproportionately face worse outcomes in key areas addressed by the NHS and Public Health Outcomes Frameworks such as employment and quality of life.

Analysis of the Understanding Society and the Life Opportunities Survey reveals that:

- People living with sight loss report having lower feelings of wellbeing.
- People living with sight loss are more likely to experience financial hardship.
- People living with sight loss face greater restrictions to their participation in education and employment.
- People living with sight loss report that they have less choice about how they spend their free time.
- Barriers remain to accessing travel, shopping and other activities.\(^ {185}\)

14.1 A significant proportion of sight loss is not treatable with medicines,\(^ {186}\) but the effects of sight loss can nevertheless be decreased by following the learning of the social model of disability. NHS services need to consider the way they are modelled for people with sight loss. Making sure health services are geared up to facilitate people with sight loss and targeting public health messaging at hard to reach groups, like those with sight loss, will improve health outcomes. People with sight loss have a particular need to avoid multiple morbidities which have a compound negative impact on health.\(^ {187}\)

14.2 To take some practical examples: those with sight loss need information in a format they can access such as large print, braille or by email or audio CD. People who cannot read their personal health information find it difficult to manage long and short term conditions, read appointment letters, or screening reminders; they are at a massive disadvantage. The majority of NHS computer systems do not record people’s preferred format to receive information and therefore do not fulfil their legal duty to provide information in an accessible format—and this must change.\(^ {188}\) In addition, all NHS correspondence should be in 14 point print.

14.3 Hospitals and GP surgeries should be designed for people with sensory loss and linked long term conditions such as dementia so that visitors remain healthy and do not needlessly fall or injure themselves. Studies have shown that fall rates can be reduced by up to 25% if sight tests, assessment of daily hazards or modifications to the environment are carried out.\(^ {189}\)

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\(^ {182}\) Dementia and Sight Loss Interest Group (2012) “Dementia and sight loss FAQs” Vision 2020

\(^ {183}\) The estimated prevalence and incidence of late stage age related macular degeneration in the UK: Christopher G Owen, Zakariya Jarrar, Richard Wormald, Derek G Cook, Astrid E Fletcher, Alicja R Rudnicka. Published in British Journal of Ophthalmology, on February 13, 2012.


\(^ {186}\) For example nystagmus (affects affects around 1 in 1,000 people: see www.nystagmus.co.uk) and retinitis pigmentosa (affects around approximately 1 in 3,000 to 4,000 people: see “RP Fighting Blindness” at http://www.rpfightingblindness.org.uk/index.php?tn=aboutrp


\(^ {188}\) E Selbey (2008) “Losing Patients” RNIB and Dr Foster reveals that 95% of people with sight loss are not offered health information in a format that they can access.

14.4 NHS staff must be trained in meeting the needs of people with sight loss—for example in basic guiding or general awareness of the need to vocalise actions. Poorly trained staff is a very commonly cited barrier faced by people with sight loss in the NHS.\(^{190}\)

**May 2013**

Written evidence from Action for M.E. (LTC 40)

**Executive Summary**

- Focusing on four terms of reference from the Health Select Committee’s inquiry, this submission is based on responses to a short survey by 252 people with the fluctuating long-term condition, Myalgic Encephalomyelitis (M.E.).
- Most respondents (72.1%) have co-morbid conditions and 39% agreed that their healthcare professional sees them just as a collection of symptoms to be treated.
- 60.9% said their healthcare professional is not aware of their social care needs and 54% said their healthcare and social care are not joined up at all. Specific examples are given.
- Around 90% have been seen by more than one healthcare professional for their M.E., and 54.2% agreed that they complemented each other in delivering patient care.
- Many respondents spoke of the anxiety, depression and isolation that comes from living with a long-term, fluctuating condition that is still little understood. Less than half said their mental health issue was considered separately from their M.E. by their healthcare professional.
- 87% said they didn’t have a care plan based on their individual needs and 37.7% said their healthcare professional valued their ideas when it came to working out treatment. Specific examples are given.

1. **Background**

   1.1 Myalgic Encephalomyelitis (M.E.) is a fluctuating long-term condition that affects around 250,000 men, women and children in the UK. It causes symptoms affecting many body systems, more commonly the nervous and immune systems. Around 25% of patients are severely affected, and may be confined to bed or unable to leave the house without the use of a wheelchair.

   1.2 Action for M.E. is the UK’s largest charity for people affected by M.E. We provide information and support, campaign for better services and more effective treatments, and drive and invest in research.

   1.3 Our submission focuses on four terms of reference from the Health Select Committee’s inquiry into the management of long-term conditions inquiry into the Management of long-term conditions inquiry into the Management of long-term conditions. It is based on responses to a 14-question survey for people with M.E. in England, devised by Action for M.E. and publicised via our Online M.E. Centre\(^{191}\) and social media sites\(^{192}\) from 4 to 30 April 2013.

   1.4 The survey was answered by 252 people with M.E. This was a good response given the short time frame. Results of the survey reflect what we expected and are broadly representative of people with M.E., with whom the charity is in daily contact.

   1.5 The duration of respondents’ illness is as follows:

<table>
<thead>
<tr>
<th>(250 respondents answered this question)</th>
<th>% of respondents</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Had M.E. for less than one year</td>
<td>2.8</td>
<td>7</td>
</tr>
<tr>
<td>Had M.E. for up to two years</td>
<td>8.4</td>
<td>21</td>
</tr>
<tr>
<td>Had M.E. for up to five years</td>
<td>18.8</td>
<td>47</td>
</tr>
<tr>
<td>Had M.E. for up to ten years</td>
<td>22.4</td>
<td>56</td>
</tr>
<tr>
<td>Had M.E. for more than ten years</td>
<td>47.6</td>
<td>119</td>
</tr>
</tbody>
</table>

2. **This Section Refers to the Ability of NHS and Social Care Providers to Treat Multi-Morbidities and the Patient as a Person Rather than Focusing on Individual Conditions.**

   2.1 Of the 244 people who answered the question “Do you have any other conditions?”
   - 27.9% (68 respondents) said no.
   - 72.1% (176 respondents) said yes.

   2.2 These conditions most commonly include fibromyalgia, anxiety, depression, asthma, irritable bowel syndrome and thyroid-related conditions.

   2.3 Respondents were asked to tick all the statements that applied to them. Responses were as follows:

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\(^{190}\) This issue was recently discussed at an RNIB roundtable and key issues are available for dissemination.

\(^{191}\) www.actionforme.org.uk

\(^{192}\) www.facebook.com/actionforme and www.twitter.com/actionforme
2.4 A respondent in Buckinghamshire said: “Some of my GPs are often biased by the diagnosis of M.E. when I try and discuss another issue or want to seek further advice or tests. It can also take some time to discuss a condition properly in light of other conditions I have, which can be difficult in a 10 minute slot.”

2.5 Action for M.E. supports the view that a holistic approach, encouraging patients to discuss more than one symptom and condition, in each appointment, would be helpful. We appreciate that GPs must operate within strict time constraints, so it would be helpful if patients with M.E. and other long-term conditions could be encouraged to book double appointments.

2.6 Respondents were asked to tick all the statements that applied to them. Responses were as follows:

<table>
<thead>
<tr>
<th>(231 respondents answered this question)</th>
<th>% of respondents</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>My healthcare professional treats me as a person, not just as an illness or illnesses</td>
<td>61</td>
<td>141</td>
</tr>
<tr>
<td>My healthcare professional sees me just as a collection of symptoms to be treated</td>
<td>39</td>
<td>90</td>
</tr>
</tbody>
</table>

2.7 Action for M.E. was pleased to see that a majority of patients agreed that their healthcare professional treats them as a person, not just as an illness or illnesses. However, the Aviva health of the nation index found that M.E./CFS was the condition that GPs find most challenging to refer for specialist attention, and has been so for the last ten years.193

2.8 We believe awareness and understanding for patients could be improved if GPs were able to access better education about M.E. Charities such as Action for M.E. and local M.E. support groups could help facilitate this.

2.9 Respondents were asked to tick all the statements that applied to them. Responses were as follows:

<table>
<thead>
<tr>
<th>(235 respondents answered this question)</th>
<th>% of respondents</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>My healthcare professional is not aware of my social care needs</td>
<td>60.9</td>
<td>143</td>
</tr>
<tr>
<td>My healthcare professional is aware of my social care needs and takes them into account</td>
<td>17.9</td>
<td>42</td>
</tr>
<tr>
<td>My healthcare and my social care are not joined up at all</td>
<td>54</td>
<td>127</td>
</tr>
<tr>
<td>My healthcare and my social care are reasonably well-integrated</td>
<td>5.1</td>
<td>12</td>
</tr>
<tr>
<td>My healthcare and my social care are very well-integrated</td>
<td>0.4</td>
<td>1</td>
</tr>
</tbody>
</table>

3. This Section looks at Examples of Effective Integration of Services across Health, Social Care and other Services which Treat and Manage Long-Term Conditions.

3.1 We asked respondents to indicate which healthcare professionals they have been treated by for their M.E.

<table>
<thead>
<tr>
<th>(241 respondents answered this question)</th>
<th>% of respondents</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP</td>
<td>99.6</td>
<td>240</td>
</tr>
<tr>
<td>Consultant specialising in M.E.</td>
<td>59.8</td>
<td>144</td>
</tr>
<tr>
<td>Consultant not specialising in M.E.</td>
<td>36.1</td>
<td>87</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>31.1</td>
<td>75</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>38.6</td>
<td>93</td>
</tr>
<tr>
<td>Psychologist or counsellor</td>
<td>32.8</td>
<td>79</td>
</tr>
<tr>
<td>Other (most common answers: alternative and private practitioners)</td>
<td>29.9</td>
<td>72</td>
</tr>
</tbody>
</table>

3.2 Around 90% of respondents (221 out of 241) had been seen by more than one healthcare professional for their M.E. We asked if these healthcare professionals complemented each other in delivering their care. Of the 227 people who answered this question:

— 54.2% (123 respondents) said yes.

— 17.6% (40 respondents) said no.
— 29.5% (67 respondents) said they weren’t sure.

3.3 We asked respondents to tell us more about their experience of this if they could, and 125 did so. Examples include:

3.4 “I had to keep repeating myself every time I saw somebody different, even if they were members of the same team, which was exhausting for someone with M.E.” (Respondent in Yorkshire)

3.5 “I access all the people via the CFS/M.E. North East service (based in Newcastle) which I was referred to via my GP. The service updates my GP well so he can offer advice mid sessions.” (Respondent in Northumberland)

3.6 “Bristol has a wonderful M.E. centre at Frenchay Hospital where there is multi-disciplinary care from medics, OTs, physiotherapists, psychologists etc. My GP (both now and where I lived before) acknowledged both that I am an expert patient when it comes to this and the superiority of the knowledge of the M.E. team, and so will go along with what they suggest.” (Respondent in North Somerset)

3.7 “The consultant copied letters to me to my GP. She referred me to a psychologist who was trained in offering CBT for M.E. patients and knew a lot about M.E. Again, he copied his assessment to my GP. I’ve also seen a psychologist for depression, referred to by my GP, and she also copied assessments to my GP.” (Respondent in Oxfordshire)

3.8 We asked respondents what social care services they had been offered in the last year.

<table>
<thead>
<tr>
<th>(240 respondents answered this question)</th>
<th>% of respondents</th>
<th>Number of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>none</td>
<td>80.8</td>
<td>194</td>
</tr>
<tr>
<td>day-time carer assisting with personal care</td>
<td>4.2</td>
<td>10</td>
</tr>
<tr>
<td>day-time carer assisting with non-personal care</td>
<td>3.8</td>
<td>9</td>
</tr>
<tr>
<td>night-time carer</td>
<td>0.4</td>
<td>1</td>
</tr>
<tr>
<td>Adaptations in the home</td>
<td>11.3</td>
<td>27</td>
</tr>
<tr>
<td>Telehealth and telecare services</td>
<td>2.1</td>
<td>5</td>
</tr>
</tbody>
</table>

3.9 A respondent in Suffolk told us: “After contacting Social Services in October 2012, I am still waiting for an appointment to discuss what care I am entitled to. Three out of five appointments have been cancelled within 48 hours of the scheduled appointment, by the social worker.”

3.10 Many respondents told us they rely on their immediate family for care.

3.11 We asked if respondents if social care professionals working with them complemented each other in delivering their care. Of the 83 people who answered this question:

— 67.5% (56 respondents) said no.
— 6% (5 respondents) said yes.
— 30.1% (28 respondents) said they weren’t sure.

3.12 We asked respondents to tell us more about their experience of this if they could, and 32 did so. None were able to offer examples of effective integration of services.

3.13 A respondent in Ipswich told us: “I have been advised by my social worker that they cannot and will not get involved with any care relating to my children and therefore any care provided for me is for me and me alone. This is particularly unhelpful, especially as I am no closer to getting a care package in place for me after making first contact with social services more than six months ago.”

3.14 A majority of people with M.E. (86%—see paragraph 3.6) told us they have been offered no social care services in the last year. Given the disabling physical symptoms of M.E., and the fact that 25% of patients are severely affected (house- or bed-bound), we believe it is important to have a national approach to improving quality and developing social care, with specific guidance for specialist conditions such as M.E.

4. This section refers to the interaction between mental health conditions and long-term physical health conditions.

4.1 Living with a long-term condition such as M.E. is no easy task. Some people with M.E. find themselves facing a mental health issue, such as depression or anxiety, as a result. We asked respondents to tell us about their experience of this, and 217 did so.

4.2 Many respondents spoke of the anxiety, depression and isolation that comes from living with a long-term, fluctuating condition that is still little understood. Some felt that their GP understood this reaction, while others are wary of discussing mental health issues alongside their M.E.

4.3 A respondent in Greater Manchester said: “I fear saying anything because my GP and healthcare professionals have so many times tried to attribute any symptoms I have down entirely to me being depressed.”
4.4 We asked respondents if their mental health issue was considered separately from their M.E. by their healthcare professional. Of the 213 people who answered this question, 23.8% (50 respondents) said this question wasn’t relevant to them. Of the remaining 163 respondents,

- 43.6% (71 respondents) said yes.
- 35% (57 respondents) said no.
- 21.4% (35 respondents) said they weren’t sure.

4.5 We asked respondents to tell us more about their experience of this if they could, and 105 did so.

4.6 A respondent in West Sussex said: “Sometimes I have felt that healthcare professionals consider my health issues and physical symptoms to be caused by depression or anxiety, which I find extremely frustrating as I feel my anxiety and depression are brought on by the M.E. and not the other way around.”

4.7 M.E. is a neurological condition, not a mental health problem. While it is encouraging to see that 43.6% (see paragraph 4.4) reported that their mental health issue was considered separately from their M.E. by their healthcare professional, just over a third did not, while more than a fifth said they weren’t sure, indicating a lack of clarity in communication from their healthcare professional. Understanding and awareness of M.E. among health professionals must be improved.

5. THIS SECTION REFERS TO THE EXTENT TO WHICH PATIENTS ARE BEING OFFERED PERSONALISED SERVICES, AND PATIENT CONTRIBUTION TO BETTER OUTCOMES.

5.1 We asked respondents if they have a care plan based on their individual needs. Of the 230 people who answered this question:

- 87% (200 respondents) said no.
- 7.8% (18 respondents) said yes.
- 5.2% (12 respondents) said they didn’t know.

5.2 We asked respondents to tell us more about their experience of this if they could, and 57 did so.

5.3 One respondent in Greater Manchester said: “Since moving to my current address five months ago I have found it very frustrating that my care support plan has not been adhered to. I have received mostly help with domestic tasks and no personal care. It has not addressed my individual needs and has also been too expensive for me to afford, meaning that I have had to cancel care and am now making a formal complaint.”

5.4 We asked respondents if they thought that their healthcare professional valued their ideas when it came to working out treatment. Of the 223 people who answered this question:

- 37.7% (84 respondents) said yes.
- 34.5% (77 respondents) said no.
- 30.9% (69 respondents) said they weren’t sure.

5.5 We asked respondents to tell us more about their experience of this if they could, and 120 did so. Some examples of effective patient contribution to better outcomes include:

5.6 A respondent in Kent said: “The fluctuations and limitations of my illness (dysphonia/sensory sensitivity) make consultations either difficult to attend or very long (always double appointments). So about a year ago my GP provided me with his surgery email address so that I can provide him with updates and relevant research material prior to consultation to inform my on-going care. As a result his knowledge of my illness and support for me has increased and my consultations with him are more constructive.”

5.7 Listening to patients as individuals, as well as through national bodies such as Healthwatch England, is key to better patient outcomes. Action for M.E. is encouraged to see that more than a third of patients have had this experience—but they are still in the minority. A fundamental shift in attitude is required.

9 May 2013

Written evidence from Baxter Healthcare (LTC 41)

Baxter Healthcare welcomes the opportunity to respond to The Health Committee’s examination of the way in which the NHS and social care system in England supports people with long-term conditions.

Baxter is a worldwide, diversified healthcare company that is known for applying innovative science and technology to develop specialty therapeutics, medical products and services that save and sustain patients’ lives. Our core purpose is to improve the quality of life of patients with rare and chronic diseases. From hospital to home, we strive to deliver better and more affordable healthcare for people worldwide.

The committee has asked following questions and our responses are below.
**THE SCOPE FOR VARYING THE CURRENT MIX OF SERVICE RESPONSIBILITIES so that more people are TREATED OUTSIDE HOSPITAL and the CONSEQUENCES of SUCH SERVICE RE-DESIGN for COSTS and EFFECTIVENESS**

There is huge scope for enabling more people with long term conditions to be treated outside of the hospital environment. Despite a wealth of evidence to support both clinical and cost effectiveness of home based therapies, uptake for many diseases is poor and is in fact declining in certain parts of the UK. In particular, the use of Peritoneal Dialysis (PD) and home Haemodialysis for the treatment of chronic kidney failure is at an all time low, despite a plethora of guidelines, evidence and quality standards supporting its use.\(^\text{194}\)

In addition to the treatment of chronic kidney failure, there are many other conditions that lend themselves to home or self-care treatment. These include parenteral anti-microbial therapy (OPAT) and immunoglobulin therapies (IG) for people suffering from immunological disorders.

One of the reasons for the decline in the uptake of home dialysis is thought to be the overestimation of the need to increase in-centre haemodialysis capacity\(^\text{197}\) which has resulted in a proliferation of centre based dialysis facilities throughout the UK. Once a centre has been commissioned, it is incumbent upon clinicians and managers to keep the facility working at capacity to ensure cost effectiveness. However, decommissioning of such services and re-allocating staff to support home dialysis patients would greatly improve the ability for more people to be treated at home.

As well as the many quality of life benefits and improved outcomes that patients report by being on a home based treatment it also generates cost savings.\(^\text{198}\) With the current focus by the NHS on QIPP, to improve patient outcomes and generate cost savings these forms of treatment need to be fast tracked and implemented on a more substantial scale so that the full benefits can be realised by patients and the NHS alike.

Another strategy that will aid the uptake of self care or home treatments is patient education, training and empowerment. Raising awareness of the availability and success of home based therapies amongst patients and the public can promote their use. This requires the commitment of all those involved in the design and delivery of services, including the physicians and nurses who discuss treatment options with their patients. High quality training and education of patients and their families before commencing and during their time on home based treatments will also improve patients’ adherence to treatment regimes and thus promote clinical and cost effectiveness of treatments.

**THE READINESS of LOCAL NHS and SOCIAL CARE SERVICES to Treat Patients with LONG-TERM CONDITIONS (INCLUDING MULTIPLE CONDITIONS) within the COMMUNITY**

Uptake of home or community based treatments varies considerably across the UK. Our experience shows that in areas where there is a belief and culture in home therapies from both clinicians and commissioners, uptake is higher. In areas where there is a lower level of belief, barriers from social care services tend to become more difficult to overcome.

The IT infrastructure that can support the treatment of patients in the community is still weak. Anecdotally, there is resistance to the uptake of remote monitoring systems due to potential liability issues on the part of the clinician. If the appropriate IT capabilities were available to enable clinicians to have remote oversight of the patients’ clinical condition, reassurance (that the patient can be managed as well outside the acute setting as within hospital) could be provided to all parties.

**THE PRACTICAL ASSISTANCE OFFERED to COMMISSIONERS to SUPPORT the DESIGN of Services which PROMOTE COMMUNITY-BASED CARE and PROVIDE for the INTEGRATION of HEALTH and SOCIAL CARE in the MANAGEMENT of LONG-TERM CONDITIONS**

To our knowledge there is very little available for commissioners to promote or support the design of services for home based therapies or to further integrate health and social care services.

We believe that should such support be made available, the uptake of home treatments for long term conditions could see an increase. The recent changes to the NHS in England, and in particular the commissioning of specialist services, has led to a relatively small number of commissioners being given responsibility for a much wider scope of specialist services. Their task of being fully informed on all available treatment options for the full range of diseases within their remit is therefore made even more erroneous. Many of these rare diseases frequently co-exist with a range of other long term conditions and patients would benefit enormously from self care and home care being offered.

The recent production of specialist commissioning service specifications should help with this, however the quality of these is variable and work needs to be done to ensure that they are consistent in approach.

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194 NICE CKD Quality Standards (QS5) March 2011  
195 NICE PD Clinical Guidelines (CG125) July 2011  
196 NICE Costing Report—Implementing NICE Guidance 125 July 2011  
The development of CQuINs should also help commissions to drive innovation and develop services for patients at home. However uptake of specific home therapy based CQuINs varies and is not yet mandatory.

It is essential that commissioners become fully engaged with Health and Wellbeing Boards to ensure a full understanding of the social care barriers that need to be addressed.

**The Ability of NHS and Social Care Providers to Treat Multi-Morbidities and the Patient as a Person rather than Focusing on Individual Conditions**

Baxter is not in a position to comment on this question however we would encourage the development of a simple mechanism for regular feedback from patients groups, individual patients and others to monitor this closely.

**Obesity as a Contributory Factor to Conditions Including Diabetes, Heart Failure and Coronary Heart Disease and how it might be Addressed**

Baxter is not in a position to comment on this question.

**Current Examples of Effective Integration of Services Across Health, Social Care and other Services which Treat and Manage Long-Term Conditions**

Baxter has a number of examples of good practice with effective integration of services to treat and manage long-term conditions. The concept of shared fields of practice, of which home dialysis is one example, requires collaboration and equity among health care professionals to ensure that the impact of change is for the benefit of the patient.

Automated Peritoneal Dialysis (APD) is a home-based therapy usually carried out by patients themselves. Training takes place in a renal unit or specialist training centre in all aspects of care. The parent unit regularly follows up patients either in clinic or in the community. However, many patients with end-stage renal disease are unable to undertake peritoneal dialysis (PD) on their own, yet would prefer treatment in their own homes. In particular, the majority of elderly patients are on the hospital based treatment, haemodialysis (HD) despite the problems and costs of transport, achieving vascular access and, often, poor tolerance of the HD process. To address this problem, assisted PD using community Healthcare Assistants has been developed. Healthcare assistants visit the patient’s home once a day to check the previous day’s treatment, check the patient’s wellbeing and set up the dialysis for the next treatment. The healthcare assistant is trained to observe for a range of signs and symptoms and to call the patient’s parent renal unit should they have concerns.

This system has been operating in the UK for almost six years and seen great success. Over 250 patients are currently using the service which represents almost 10% of the PD population, all of whom would not be able to have a home based treatment if the service was not available. The system required collaboration and team work between the NHS renal unit, the home care provider and the nursing support organisation to enable seamless high quality care.

**The Implications of an Ageing Population for the Prevalence and type of Long Term Conditions, together with evidence about the Extent to which Existing Services will have the Capacity to meet Future Demand**

The implications of an ever increasing elderly population will inevitably impact on the prevalence and type of long term conditions experienced. In many long term disease areas, as treatments improve, patients live for longer and thus are susceptible to a greater number of co-morbidities. For example people with the bleeding disorder haemophilia, would have an average survival of 15 years if born in 1960, whereas today they have a normal life expectancy as techniques such as prophylaxis are now used to better manage their condition. In addition, treatments for long term diseases are now offered to older patients than previously. Thus, more patients are being treated for more diseases with more treatments than before.

Capacity planning therefore needs to be much more holistic than in the past, and consider all available locations for care. Integration between primary, secondary, community and social care needs to be factored into capacity planning and the use of home care considered for a greater proportion of patients.

Remote monitoring systems and electronic health records should be considered as integral to the support of patients and these must be accessible to patients as well as clinicians in both primary and secondary care.

Currently there are many perverse financial incentives that exist, preventing the uptake of home treatments. Frequently the acute hospital is financially penalised for moving care out of the hospital setting, despite home treatments being clinically effective and more cost effective and than in-centre alternatives. One example of this is the use of outpatient anti-microbial therapy (OPAT) for the treatment of multi-resistant TB.

**The Interaction between Mental Health Conditions and Long-Term Physical Health Conditions**

Baxter is not in a position to comment on this question.
Ev w84  Health Committee: Evidence

THE EXTENT TO WHICH PATIENTS ARE BEING OFFERED PERSONALISED SERVICES (INCLUDING EVIDENCE OF THEIR CONTRIBUTION TO BETTER OUTCOMES)

Baxter is not in a position to comment on this question however we would encourage the development of a simple mechanism for regular feedback from patients groups, individual patients and others to monitor this closely. The regular use of patient reported outcome and experience measures should become routine practice.

9 May 2013

Written evidence from the British Association for Counselling and Psychotherapy (LTC 42)

The British Association for Counselling and Psychotherapy (BACP) would like to submit the following response to the Health Committee’s Inquiry into the Management of Long-term Conditions (LTCs). BACP’s response will focus on the interaction between mental health conditions and long-term physical health conditions and the use of psychological therapies to ameliorate the impact of psycho-bio-social problems.

1. EXECUTIVE SUMMARY

— Research evidence consistently demonstrates that people with long-term conditions, such as diabetes, are two to three times more likely to experience mental health problems than the general population. Co-morbid mental health problems can result in poorer clinical outcomes, lower quality of life and reduced ability to manage physical symptoms effectively.

— Good evidence shows that management of mental health problems can reduce the need for GP appointments, hospital stays and outpatient procedures.

— Talking therapy services have been shown to improve outcomes for people with long-term conditions and mental health issues.

— Despite the evidence, people with long-term physical health conditions are rarely referred for psychological interventions.

— Integrating access to talking therapies into the care pathways of those who suffer with these conditions will improve outcomes and can help secure long-term cost savings.

— BACP believes it is imperative to support both the psychological and physical needs of people with long-term conditions by integrating mental and physical healthcare more closely.

— The value of counselling as an effective support mechanism for people living with long-term conditions should be recognised and access to counselling for people, including children and young people, with LTCs should be expanded.

2. FACTS: LONG-TERM CONDITIONS AND MENTAL HEALTH

General

— 30% of people with a long-term medical condition also have a mental health problem, with 20% of people with long-term conditions suffering from depression alone.\textsuperscript{199} People with two or more long-term conditions are seven times more likely to have depression than people without a long-term condition.\textsuperscript{200}

— Research shows that children suffering with long-term conditions are twice as likely to develop emotional or conduct disorders.\textsuperscript{201}

— Between 12% and 18% of all NHS expenditure on long-term conditions is linked to poor mental health and wellbeing—between £8 billion and £13 billion in England each year.\textsuperscript{202}

— Co-morbid mental health problems raise total health care costs by at least 45% for each person with a long-term condition and co-morbid mental health problem.\textsuperscript{203}

— Patients with long-term conditions who were also receiving treatment for depression or anxiety had average monthly medical costs that were between 33% and 169% higher over a range of conditions.\textsuperscript{204}

Chronic Obstructive Pulmonary Disease

— Mental health problems are around three times more prevalent among people with chronic obstructive pulmonary disease (COPD). Anxiety disorders are particularly common; for example panic disorder is up to 10 times more prevalent than in the general population.\textsuperscript{205}

\textsuperscript{199} Department of Health (2011) Talking Therapies: A four-year plan of action
\textsuperscript{200} The Kings Fund (2012) Long-term conditions and mental health: The cost of co-morbidities
\textsuperscript{201} Office for National Statistics (2008) Health expectancies at birth & at age 65 in the United Kingdom
\textsuperscript{202} The Kings Fund (2012) Long-term conditions and mental health: The cost of co-morbidities
\textsuperscript{203} Ibid.
\textsuperscript{204} Ibid.
\textsuperscript{205} Ibid.
— Those with cardiac problems are three times more likely to die of these causes if they also suffer from depression than if they do not.\textsuperscript{206}

— Research has shown that people with heart disease are more likely to suffer from depression, and when they do are at greater risk of more heart disease events.\textsuperscript{207}

**Diabetes**

— Recent estimates suggest that around 430,000 people who have depression alongside their diabetes are receiving sub-optimal care and account for a significant number of GP and outpatient consultations, A&E attendances and inpatient bed days.\textsuperscript{208}

— Comorbid depression is associated with a 50–75\% increase in health spending among diabetes patients.\textsuperscript{209}

3. **THE ROLE OF TALKING THERAPIES FOR PEOPLE WITH LONG-TERM CONDITIONS**

— Long-term physical health conditions and mental health are closely linked. Likewise, people who suffer from a mental health problem are more likely to develop long-term physical health problems.\textsuperscript{210}

— Talking therapy services have been shown to improve outcomes for people with long-term conditions and mental health issues. Integrating access to talking therapies into the care pathways of those who suffer with these conditions can improve outcomes and can help secure long-term cost savings by reducing the heavy use of NHS resources by people with these conditions, particularly in an acute inpatient setting.\textsuperscript{211}

— Research has shown that the addition of psychological interventions into usual care for Chronic Obstructive Pulmonary Disease (COPD) can improve completion rates of post-rehabilitation exercise programmes.\textsuperscript{212}

— Offering a range of psychological therapies during cardiac rehabilitation has been proven to be both successful in reducing anxiety and depression and is acceptable to patients.\textsuperscript{213}

— Long-term conditions can be difficult to cope with, often leading many individuals unable to make the important daily decisions needed for their condition, exacerbating their problems. Counselling can help build resilience to the challenges of daily decision making and improve wellbeing. Diabetes UK has said for example: “Counselling, emotional and psychological support services are an essential part of routine diabetes care and specialist services for those with more complex clinical and psychological needs.”\textsuperscript{214}

4. **CURRENT PROVISION**

— In February 2011 the Government’s Talking Therapies: A four year plan of action prioritised the expansion of the Improving Access to Psychological Therapies (IAPT) programme to include people with Long Term Conditions (LTC).

— Fifteen Therapy Teams were selected in February 2012 to become IAPT LTC Pathfinder Sites which are due to be evaluated in March 2013 and in September 2013.

— The Government hopes that approximately three million people with long-term conditions will be able to benefit from telehealth and telecare by 2017. Tele healthcare aims to support people to manage and monitor their condition at home, and reduce the need for visits to their GP practice and hospital.\textsuperscript{215}

5. **RECOMMENDATIONS**

— Long-term conditions are conditions which blur the line between mental and physical health. The Government’s increasing recognition that mental and physical healthcare in the NHS needs to be joined-up and given parity makes sense for long-term conditions. The move to include long-term conditions into IAPT is also promising, opening up access to psychological therapies for many people suffering from a variety of conditions from diabetes to coronary heart disease.

\textsuperscript{206} Department of Health (2011) Talking Therapies: A four-year plan of action

\textsuperscript{207} Ibid.

\textsuperscript{208} Ibid.

\textsuperscript{209} Ibid.

\textsuperscript{210} Scottish Executive (2006) Delivering for Mental Health

\textsuperscript{211} Department of Health (2011) Talking Therapies: A four-year plan of action

\textsuperscript{212} Stern, M (2010) The effect of inclusion of a clinical psychologist in pulmonary rehabilitation on completion rates and hospital resource utilisation in COPD.

\textsuperscript{213} Childs, A (2010) Meeting the psychological needs of cardiac patients: an integrated stepped-care approach within a cardiac rehabilitation setting. The British Journal of Cardiology, 17:4: 175–9

\textsuperscript{214} Depression Alliance et al (2012) Twice as Likely: Putting Long-term Conditions and Depression on the Agenda

The psychological therapies offered to those individuals with long-term conditions need to be wide-ranging; long-term conditions are varied and whilst depression and anxiety are often the mental health issues that are commonly encountered, flexibility is needed so that a range of evidence informed therapies can be offered to improve the mental health of individuals with long-term illnesses.

Counselling has been shown to be an effective intervention for loss (almost twice as effective as cognitive-behavioural therapy\(^{216}\)) something which is particularly relevant to those suffering with long-term conditions, as they deal with consequences of life-limiting conditions. Counselling’s value to people with long-term conditions needs to be given further consideration in future Government proposals in this area.

BACP would welcome further resources to be made available, outside of the IAPT programme, for age-appropriate therapy for children and young people living with long-term conditions. BACP believes that children and young people should be offered support in an appropriate setting, such as the home, hospital, school or specialist unit and tailored to their physical needs depending on their condition. Access to therapy must be open ended, with easy access and referral allowing for children to be able to drop out in periods of wellness.

6. BRITISH ASSOCIATION FOR COUNSELLING AND PSYCHOTHERAPY

As way of background, The British Association for Counselling and Psychotherapy (BACP) is the leading and largest professional body for counselling and psychotherapy in Europe, with a membership of over 38,000 practitioners, drawn from the various professional disciplines in the field of counselling and psychotherapy and based in a range of settings.

All BACP members are bound by the Ethical Framework for Good Practice for Counselling and Psychotherapy and within this, the Professional Conduct Procedure.

7. FURTHER INFORMATION

Should the Committee be seeking further oral evidence, BACP would be delighted to provide additional information about psychological therapies long-term conditions.

9 May 2013

Written evidence from the Society of Chiropodists and Podiatrists (LTC 44)

EXECUTIVE SUMMARY

The Society of Chiropodists and Podiatrists, the professional body and trade union which represents over 10,000 Chiropodists and Podiatrists, wishes to respond to your invitation to submit evidence to its inquiry into the management of long term conditions.

The Society of Chiropodists and Podiatrists is well placed to comment on the treatment of long term care as it is, or should be, an integral part of the care pathway relating to the treatment of a number of long term conditions. These range from Diabetes to Peripheral Arterial Disease and Rheumatoid Arthritis. Moreover its members, whether employed by the NHS or in private practice, work in a range of settings—community and acute.

The Society found that the current mix of service responsibilities does not always serve the patient best nor are services sufficiently well organised so that community and acute services are well integrated. For example those with diabetes often lack the availability of a multidisciplinary footcare team (MDFT) as only 45.5% of hospital sites currently have one. In terms of evidenced best practice each MDFT should be linked to a Foot Protection Team working in both the community and the acute sector. This lack of provision is despite clear and accepted research showing that the integration of these sectors generates better patient outcomes and saves money (up to £34 million a year). The submission includes examples of effective integrated provision.

Similarly, people with Peripheral Arterial Disease are often not diagnosed in the early stage of disease progression- an early diagnosis could be made by a Podiatrist. The 10 year mortality for those with Peripheral Arterial Disease, at approximately 50%, is worse than those for other serious conditions such as breast cancer. However better assessment, diagnosis and management through the provision of community Podiatry and other services would lead to a reduced mortality rate and lead to more appropriate referrals to vascular clinics.

Similarly, despite NICE noting that all people with Rheumatoid Arthritis should have access to foot health services, only half of all rheumatology departments report basic foot health services for their patients and less than one in 10 have formal care pathways or mechanisms for referral to foot health services. Better integrated NHS primary and acute care, including the provision of foot orthoses (insoles) which have the potential to prevent major functional and structural foot problems, would result in earlier diagnosis and better treatment.

resulting in estimated productivity gains to the economy of £31 million from reduced sick leave and lost employment.

The revised NHS Constitution’s first guiding principle declares that the NHS has a duty to promote equality through the services it provides. The Society of Chiropodists and Podiatrists therefore urges that full foot health services provision be extended throughout England rather than the current rolling back and cutting of services. Foot health services have a large part to play in improving the quality of life and longevity of an ageing population with long term conditions through their ability to diagnose and treat foot conditions, make timely onward referrals and via the delivery of health promotion advice to prevent symptoms. Despite providing guidance to commissioners, for example on best practice on “Putting Feet First in Diabetes Care” for the attention of CCGs and Health & Wellbeing Boards, the Society fears that the new NHS may lead to fragmentation and not better practice in treating those with long term conditions.

**DIABETES**

1. Currently 2.9 million people (4%) in the UK have been diagnosed with diabetes. It is estimated that a further 850,000 are either undiagnosed or have no confirmed diagnosis. Epidemiologists estimate that this figure will have increased to 5 million by 2025 and to 10% of the whole population by 2032.

2. The prevention and management of foot disease in people with diabetes is an essential component of every commissioned diabetes pathway. The challenge for the NHS is to ensure these services are in place and therefore reduce the incidence of amputation.

3. 5–7%, (130,000–180,000) of people with diabetes will experience a foot ulcer at some stage in their lives. At any single time there will be over 60,000 people in England with a foot ulcer. Evidence shows foot complications account for more hospital admissions than any other complication of diabetes; 500,000 hospital bed nights are taken up by foot complications per year. Moreover the mortality rate for people with diabetic foot ulcers is third only to pancreatic and lung cancers at five years.

4. The National Diabetes Inpatient Audit (2012) found that 9.3% of patients had a foot complication on admission, of which 53.3% had input from a multidisciplinary foot team within 24 hours. The audit found that 1.6% of patients developed a foot lesion during their admission which was reduced from 2.2% in 2010.

5. The current number of amputations is rising from 5,700 in 2009–10 to over 6,000 in 2010–11. It is reported that given the increasing incidence of diabetes there will be over 7,000 amputations performed on people with diabetes in England by 2014/15, unless urgent action is taken.

6. There is currently a high variability in incidence of lower limb amputation, both minor and major, evident across commissioning organisations. For minor amputations the variation is tenfold- from 0.3 per thousand adults to 3.5, with an average of 1.4 per thousand. For major amputations the range is from 0 to 1.8 per thousand, with an average of 0.7 per thousand adults.

7. Jeffcoate et al (2012) concluded that the 10-fold variation in amputation rates between commissioning organisations in England related largely to the structure of available specialist services. It has also been widely reported, and accepted by Department of Health Ministers, that 80% of amputations are preventable.

8. NICE clinical guideline 10 (2004) set out a footcare management plan in order to reduce the risk of problems occurring in those with diabetes. Similarly Diabetes UK put forward four simple steps to reducing amputations:
   - All people with diabetes should have annual foot checks, be told and understand their risk score, and know how to look after their own feet.
   - People in all areas should have swift access to Foot Protection or Multidisciplinary Foot Care Teams, which have been shown to significantly reduce levels of risk.

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218 State of the Nation 2012 England, Diabetes UK


222 Based on the annual increase in the number of episodes of inpatient care where amputations have occurred among people with diabetes. Source: The Information Centre for Health and Social Care, Hospital Episodes Statistics. 2007/08–2010/11

223 Parliamentary Question, tabled by Keith Vaz MP, and answered by Paul Burstow, Minister of State for the Department of Health on 06/02/2012. http://www.publications.parliament.uk/pa/cm201213/cmhansrd/cm120213/text/cm120213w0005.htm


225 As Earl Howe said in the House of Lords on 14th July 2011 during a Starred Question debate on Diabetes: “I have an astonishing figure…on average 73 amputations of lower limbs occur every week in England because of complications to do with diabetes. It is estimated with the right care 80% of amputations carried out on patients suffering with diabetes would be preventable.”


227 Putting Feet First, Diabetes UK, 2012
— People with diabetes who go into hospital, for whatever reason, should have their feet checked on admission and throughout their stay.

— Healthcare professionals need a greater understanding of the importance of diabetic footcare.

9. NHS Diabetes and Diabetes UK commissioned the landmark publication, Footcare for People with Diabetes: The Economic Case for Change.\textsuperscript{228} It has calculated that the total expenditure within the NHS on diabetic foot care in 2011 was between £573 and £686 million. This does not include the economic impact from disability payments, reduced tax revenues and re-housing.

10. Clear clinical evidence was provided that showed the importance of diagnostic tests, early referral to specialist care, the use of multidisciplinary teams and cardiovascular screening, all of which can reduce amputation and mortality rates. NICE guidance Clinical Guideline 119\textsuperscript{229} backs this up by stating in its list of key priorities that “ongoing care of an individual with an ulcerated foot should be undertaken without delay by a multidisciplinary foot care team.”

11. Evidence was cited for a multidisciplinary foot care team (MDFT) approach for inpatients with diabetes in Southampton which led to a reduction in the length of inpatient stays from 50 days to 18 days. Not only were patient outcomes improved but annual savings to the NHS of £888,979 were generated. In another example, at The James Cook Hospital in Middlesbrough, a MDFT generated annual savings of £249,459. Likewise an 11 year study at Ipswich Hospital found that the incidence of major amputation per 10,000 people with diabetes fell by 82% following the introduction of an inpatient MDFT. The incidence of minor amputation per 10,000 people with diabetes fell by 21%.

12. By standardising best practice multidisciplinary team working throughout the UK the NHS could make net savings and reduce the number of amputations. Marion Kerr estimated, for example, that if there were a 50% reduction in amputations by 2018, the savings generated are calculated as £42 million over the five year period from 2013.\textsuperscript{230} Meanwhile the National Audit Office has estimated that a reduction of late referrals to specialist foot teams by 50% could save at least £34 million each year through the reduction of amputations.\textsuperscript{231}

13. The Society of Chiropodists and Podiatrists has long had an on-going concern about whether the issue of amputations, and consequent mortality, receives the level of public attention it warrants given that the mortality rates for people with diabetic foot ulcers and those having amputations are greater than those with breast or prostate cancer.\textsuperscript{232} By prioritising best practice in long term conditions, as well as meeting the Nicholson Challenge, there is an ideal opportunity to right this wrong. To do so would also be in line with two of the five outcomes for the NHS identified within the “Mandate for NHS England: preventing people from dying prematurely and enhancing quality of life for people with long term conditions.”\textsuperscript{233} Foot health services are struggling to manage current demand and the predicted increase in the prevalence of diabetes will lead to overload- consequently a workforce review is urgently required.

**Peripheral Arterial Disease**

14. Peripheral Arterial Disease (PAD) is common in the UK population in those aged 55 or over, but is often not diagnosed until it is moderate or severe. Outcomes have been poor, with substantial cardiovascular mortality and morbidity and, to a lesser degree, chronic lower limb wounds and amputation.\textsuperscript{234} 15. PAD has recently been included in NICE guidance (2012)\textsuperscript{235} and Quality and Outcomes Framework indicators.\textsuperscript{236}

16. Fox (2013)\textsuperscript{237} postulated that with better assessment, diagnosis and management of PAD in community services, there could be fewer, but more appropriate referrals to vascular clinics. This could in turn free up surgical appointment slots to allow rapid access for people with critical limb ischaemia, thus unlocking improvement at no significant additional cost.


\textsuperscript{231} The management of adult diabetes services in the NHS—National Audit Office May 2012


\textsuperscript{235} National Institute for Health and Clinical Excellence (2012) Lower Limb Peripheral Arterial Disease. NICE guideline CG147. www.nice.org.uk/cg147


17. PAD’s 10 year mortality, at approximately 50%, is worse than those for other serious conditions such as breast cancer and malignant melanoma of the foot. This may be due to a lack of early diagnosis and effective clinical management.238

18. As up to 50% of those with PAD are asymptomatic it is important that those with risk factors are screened early to enable lifestyle changes to take place, thus enabling a reduction in hospital admissions, amputations and premature death; and improvements in quality of life and life expectancy. Podiatrists are able to diagnose PAD and enable onward vascular referral.

**Rheumatoid Arthritis**

19. Rheumatoid Arthritis is a chronic inflammatory joint disorder that affects approximately 580,000 people in England, which suggests that over 690,000 people in the UK live with the condition.239 Females are up to four times more likely to develop the condition than men. Up to 90% of people with Rheumatoid Arthritis have some form of disease related foot involvement. Long standing inflammation leads to structural deformity and soft tissue lesions, which in turn generates areas of pressure that may result in foot ulceration.

20. NICE (2009)240 and Scottish Intercollegiate Guidelines Network (2011)241 concurred that all people with Rheumatoid Arthritis should have access to foot health services. Yet only half of all rheumatology departments report basic foot care services for their patients and less than 1 in 10 have formal care pathways or mechanisms for referral to foot care services.242

21. The National Audit Office’s report, Integration Across Government,243 stated that better integrated NHS primary and acute care would result in earlier diagnosis and treatment of patients with the Rheumatoid Arthritis, ultimately resulting in productivity gains to the economy of £31 million from reduced sick leave and lost employment.

22. The Podiatry Rheumatic Care Association244 recommended that early intervention through the provision of foot orthoses (insoles) has the potential to prevent major functional and structural foot problems providing joint mobility is still good. They cited studies which demonstrated that through the intervention of foot orthoses, a sustained effect is had on the foot structure and stability of the joints of the foot, thus reducing pain and improving mobility.

23. There is potential to prevent major functional and structural foot problems by providing foot orthoses early on in the disease process. However, because foot changes have the potential to occur within two years of disease onset it is essential that patients are referred for assessment of foot function as early as possible following diagnosis. Similarly NICE guidance245 recommended that functional insoles and therapeutic footwear should be available for all people with rheumatoid arthritis if indicated.

9 May 2013

**Written evidence from the National Ankylosing Spondylitis Society (NASS) (LTC 45)**

**SUMMARY**

— Ankylosing Spondylitis (AS) is a painful, progressive form of inflammatory arthritis which affects two—five adults per 1,000 in the UK, or approximately 200,000 people.

— This is around twice the number of people with MS, but AS is much less well known. It is one of a huge range of musculoskeletal disorders (MSDs) which although come under the Department of Health’s definition of a long term condition, have been highly under prioritised by the NHS, often in the past having been ignored by PCTs as a long term condition.246


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— Key problems are inadequate training on MSDs in primary care, insufficient awareness of MSDs, delayed diagnosis and referral for specialist treatment and ill-defined patient pathways. All of these key problems apply directly to people with AS’s experience of care in the UK.

— Of all health conditions, MSDs are the single biggest cause of disability in the UK, at 31.3% — nearly one third of the entire burden of disability. When combined with mental health disorders, which is often the case with chronic painful musculoskeletal conditions and depression, they make up over half the total burden of disability.

1. Despite there being over 200,000 people in the UK with ankylosing spondylitis there are currently no NICE quality standards or clinical guidelines that cover this incurable, lifelong and painful condition. We strongly believe the lack of clinical guidelines on AS to be exacerbating the long delays in diagnosis experienced by people with AS. We also believe that the current low awareness of AS amongst healthcare professionals at primary care level would be significantly improved by the introduction of clinical guidelines, which would also help more patients access the right treatment at the right time.

2. There are currently only two NICE Technical Appraisals on AS, TA143 and TA233, but these are drug therapies that have been approved by NICE for people with “severe active” AS. The NICE guidance on low back pain (CG 88) does in fact specifically preclude ankylosing spondylitis with its definition of “the management of pain that has lasted for longer than six weeks but less than a year”. The 200,000 people with AS in the UK are therefore left with very little NICE guidance, which currently only covers those most severely affected by the condition. AS is not a rare condition, affecting one in 200 people and therefore it seems grossly unfair that there are Department of Health recommendations with NICE for quality standards for both Parkinson’s disease and multiple sclerosis both which affect fewer people than AS.

3. The lack of specific NICE clinical guidance on AS makes it very unlikely that NICE Quality Standards on AS will be developed and outcomes measured in the near future and this has been recently confirmed on the 25th February 2013 by the Minister for Health, Norman Lamb MP in an adjournment debate at the House of Commons.

4. AS is often missed by GPs and the average delay from symptom onset to diagnosis is a shocking eight and eleven years. In this time irreversible spinal damage has often occurred and opportunities to ensure that the patient’s quality of life is optimised have been lost. Back pain is the second most common reason for visiting a GP; therefore inflammatory back pain (IBP), which is relatively rare, can get missed. Traditional screening criteria for back pain often do not consider IBP as a diagnosis.

5. NASS has published a good practice guide for the diagnosis and treatment of AS written by a group of experts, including both rheumatologists and physiotherapists. This report, called “Looking Ahead” can be read at http://www.nass.co.uk/research/published-reports/ and it makes important recommendations.

6. NASS wants all GPs to consider the ASAS criteria for early AS in all patients who are less than 40 and who have had back pain for more than three months. These criteria should be widely publicised to GPs and integrated in all IT systems and technology used by GPs when assessing a patient. GPs should also be encouraged to search their databases for all patients under 40 with back pain for longer than three months and reassess their diagnoses according to these criteria.

7. If the ASAS criteria are met immediate referral should be made to a rheumatologist and MRI scans should be used to establish an early diagnosis before waiting for damage to the skeleton to show up on an x-ray. Early diagnosis allows early access to specialist treatment, including physiotherapy and hydrotherapy which are central to the treatment of AS. Biological therapies, or anti-TNF drugs, can also often effectively manage the disease and prevent costly recurring visits to the GP. They are also more likely to enable that person to stay in work and be economically active. They should, therefore, be made available to all patients who meet the NICE criteria.

8. Once a diagnosis has been established it is important that patients receive regular follow up. Recent research found that at least a third of patients with a confirmed diagnosis of AS are not receiving any secondary care follow up. This must be addressed so that all people with AS have access to the best treatment options available and therefore benefit from improved disease outcomes.

9. We have been heartened to hear that in discussions with Martin McShane and his team in Domain 2 of the NHS Outcomes Framework has adopted a framework known as the “House of Care” in order to try and make person-centred care a reality for people. We sincerely hope that patient led, voluntary organisations like NASS are included in the building of services making this “person-centred care” rhetoric a reality by


Back pain of > 3 months with 4 of these criteria:—
Age less than 40
Insidious onset
Improves with exercise
No improvement with rest
Pain at night (improves on getting up)


emphasising the importance of listening to each individual patient and their goals, creating outcome measures based on their actual experiences rather than what services are available.

10. Regular exercise is a cornerstone of treatment for someone with AS and also reduces the need for unplanned outpatient appointments. NASS runs a network of over 85 local branches throughout the UK. These branches provide access to at least 40 hours of group physiotherapy and hydrotherapy each year—that’s almost seven times the average number of hours provided by the NHS. This represents a resource for patients that should be used by commissioners. We believe that our branch network demonstrates what can be achieved by a charity working in partnership with the NHS, however these community groups are often under threat from hydrotherapy pool closures and hospitals starting to charge to use facilities out of hours.

11. Self-care, such as that supported by our branch network, is crucial in long term conditions like AS and is also cost effective for the NHS. The Department of Health’s Musculoskeletal Framework published in 2006 and more recently the national outcome for Domain 2, highlights the importance of self-care in helping patients stay healthy and reducing the risk of new problems. Despite this many PCTs in the past have not provided information to patients to support self-care, or worked with voluntary organisations to support patients with these conditions. We are hopeful that this status quo will not continue with the Clinical Commissioning Groups.

12. Clinical Commissioning Groups and Health and Wellbeing Boards must all gain a better understanding of AS and properly recognise need in local areas. Commissioners should be encouraged to provide education and training on AS and support an improvement to GP training in this area. Commissioners should also provide information to patients on self-management of their conditions.

9 May 2013

Written evidence from the British Association and College of Occupational Therapists (LTC 46)

INTRODUCTION AND SUMMARY

The College of Occupational Therapists, the professional body representing over 29,000 occupational therapists and OT staff, is pleased to respond to the Health Select Committee Inquiry into the Management of Long Term Conditions.

— Occupational therapists (OTs) work in the NHS, local authority social care services, housing, schools, prisons, voluntary and independent sectors, and vocational and employment rehabilitation services. They play a vital role every day in the delivery of care and support services, working with people of all ages with a wide range of occupational problems resulting from physical, mental, social or developmental difficulties.

— Occupational therapists assist those with long-term conditions by using their knowledge and skills in prevention and early intervention; reablement and rehabilitation; reducing the effects of a disabling environment, and enabling people’s safety and independence.

— Occupational therapists prevent unnecessary hospital admissions and enable treatment to take place in the community, through early supported discharge and reablement services.

— Occupational therapists take a functional approach when working with individuals, helping to treat the person “as a whole” by recognising all their needs together. This promotes increased integration across health, social care and employment, resulting in cost-savings and more effective care.

— As the population ages OTs will be able to help meet and manage demand for services by working with older people to support both physical and mental wellbeing. COT believes it is important to tackle inequalities in health in order to manage future demand for services.

— Occupational therapists treat the psychological as well as the physical aspects of disease and disability, which improves wellbeing and aids the effective management of long-term conditions.

— Occupational therapists contribute to obesity prevention and management by working with “high risk” groups and helping people to address eating habits and activity levels.

— As well as defining long term conditions, COT suggests that it would be useful to define health and health promotion, in order for interventions for people with long term conditions to be effective.

1. The scope for varying the current mix of service responsibilities so that more people are treated outside hospital and the consequences of such service re-design for costs and effectiveness

1.1 The College of Occupational Therapists believes that OTs can play a greater role in supporting people to be treated outside of hospital. OTs are already heavily involved in enabling community care and COT believes that investment in OTs is cost effective, saving the NHS money in both the short and long term.

1.2 The government should utilise occupational therapists’ skills, which are already available, and further develop their roles, in order for more people to be treated outside hospital. They should also take greater account of occupational therapists’ ability to use both a medical and a social model of health and disability when working with clients. Finally, the government should plan for the long term, so that the impact of interventions can be evaluated comprehensively.
2. The readiness of local NHS and social care services to treat patients with long-term conditions (including multiple conditions) within the community

2.1 The pattern of service provision for people with long term conditions appears to be piecemeal, with some examples of good practice and other reports of lack of investment and coordination of services. One of our members reports, for example, that specialist services provided by acute services are not followed up in the community, even when such intervention would only need to be brief. COT would like to see a consistent approach to service design and delivery, taking into account the examples of good practice which are available. For example:

2.2 Occupational therapists are involved in Early Supported Discharge (ESD) services for people who have had a stroke. “A National Institute for Health and Clinical Excellence assessment of its (Camden Reach Early Discharge Service) approach showed that savings of £83,000 per 100,000 population can be achieved through reduction of an average of 10 stroke bed days and by reducing ongoing dependence on social care packages by an average of 19 hours per week.”

2.3 Occupational therapists working for social services also enable patients to return to, or remain in, the community by providing home adaptations, making moving and handling recommendations and delivering reablement services. Such activities also result in cost-savings. For example, one example of a reablement service including occupational therapy showed that outcomes improved for citizens over a four week period, increased the skills of rehab support workers and saved an estimated £780 per citizen over the reablement period.

2.4 Occupational therapists are employed in A&E departments to prevent unnecessary admissions by conducting rapid assessments, arranging discharge home with the necessary care arrangements and equipment in place, or transferring patients to more appropriate services by using links with intermediate care and social services. This results in significant cost savings.

3. The practical assistance offered to commissioners to support the design of services which promote community-based care and provide for the integration of health and social care in the management of long-term conditions

3.1 COT would like to see greater AHP involvement in commissioning decisions, alongside GPs, nurses and doctors based in secondary care. Useful sources of assistance in the commissioning of community based care are the Allied Health Professions (AHP) AHP Toolkits, developed by the AHP Leads working with NHS London. “They define exactly how each AHP, including occupational therapists, contribute to each step of the pathway, and base this on clear evidence.” (COT 2013 p7).

3.2 The toolkits have been produced for six major care pathways, including stroke, musculo-skeletal conditions, cancer and diabetes.

4. The ability of NHS and social care providers to treat multi-morbidities and the patient as a person rather than focusing on individual conditions

4.1 Occupational therapists tend to take a functional approach when working with individuals, taking into account how they may be affected physically, cognitively and psychologically by their condition or conditions. This helps the person to be seen “as a whole”; “Techniques used may be rehabilitative (enabling a person to regain reduced abilities) educational (for example, managing fatigue that may be associated with the condition) or adaptive (for example, finding new, easier ways of carrying out tasks, often using equipment or assistive technology).”

4.2 Many services are commissioned based on outcomes which relate to single conditions, and this negatively affects the ability of NHS and social care providers to treat people who have several long term conditions. Commissioning problems could be addressed by using functional as well as condition specific outcome measures. The NHS Outcomes Framework does include “functional ability” as one of the overarching indicators for long term conditions, but this is then measured by using employment as an indicator. Although employment is important, functional ability incorporates many factors such as mobility, self care, domestic activities.

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would like to see a greater variety of functional and occupational performance measures included within the framework.

4.3 One way in which occupational therapists work with people who may have several long-term conditions is through their approach to vocational rehabilitation. In relation to this, the AHP Advisory Fitness for Work Report has been launched recently. This tool has been developed to enable AHPs to advise on the functional impact of a patient’s condition on his/her ability to work and to recommend workplace adjustments. The focus on functional ability helps to tailor intervention to the person’s needs, rather than towards specific condition(s).257

5. Obesity as a contributory factor to conditions including diabetes, heart failure and coronary heart disease and how it might be addressed

5.1 Occupational therapists are well placed to contribute to obesity prevention and management. For example in primary care, they have a role in prevention of obesity in “high risk” groups, such as people with disabilities. In tertiary care the occupational therapy role within bariatric teams includes addressing problems with daily activities, improving mobility within home and community, increasing physical stamina, teaching relaxation and communication skills and use of techniques such as motivational interviewing to change activity patterns and eating habits.258 Occupational therapists also have a major role in the prescription of bariatric equipment as necessary, making the judgement between ensuring safety and optimising activity levels.

5.2 COT would like to see occupational therapists role in health promotion and prevention work, such as obesity management recognised, for example, by including it in service and person specifications.

6. Current examples of effective integration of services across health, social care and other services which treat and manage long-term conditions

6.1 Occupational therapists have a significant contribution to make to the provision of integrated care, working across health, social care, housing, employment, charity and independent sectors.259

6.2 One example of effective integrated care is the Neuro Case Management Service in Sheffield. The service integrates care across health, social and voluntary sector, whilst providing personalised care. The team consists of three occupational therapists and one nurse, working as case managers, with the four health professionals being responsible for a case load of over 800 people. The service has been commissioned to provide:

- Long term case management and care navigation without discharge.
- Management of those people with a neuro diagnosis (who may also have co-morbidities) who have complex needs.
- Self-management and reduction of unplanned GP activity and hospital admissions.
- Reduction of duplication regarding rehab referrals made across an uncoordinated pathway.
- Timely medical, rehab and social care intervention to maintain status.
- Proactive MDT network plan to coordinate current and future needs.
- Holistic assessment that links with health, social and 3rd sector and employment services.260

7. The implications of an ageing population for the prevalence and type of long term conditions, together with evidence about the extent to which existing services will have the capacity to meet future demand

7.1 The implications of an ageing population include that more people will be living with several long-term conditions including dementia, musculo-skeletal conditions and general frailty. More people will also be living with mental health issues.

7.2 Many recommendations have already been made on how to improve capacity and quality of care for people with dementia.261 The role which occupational therapists can play includes:

- Providing non-pharmacological management of symptoms such as behavioural disturbance and depression.
- Working as case managers.
- Assisting home carers to work “with” rather than “for” people with dementia.


— Discharge planning.
— Ensuring that developments for example in telecare and assisted housing are appropriate for people with dementia.
— Providing “in-reach” services for people in care homes, in order to enable meaningful occupation.262

7.3 As the population ages, it is important that older people’s mental well-being is supported and maintained. OTs can improve mental well-being by promoting physical activity when working with older people, as evidenced by NICE Public Health Guidance 16.263 OTs also have a key role in reablement, admission avoidance and falls prevention.264

7.4 In the longer term, it will be important to improve health equality, both as an end in itself and to reduce the overall increases in demands on services brought about by an ageing population. This will require the social determinants of health to be addressed by occupational therapists and other health professionals.265

7.5 COT would like the government to recognise and promote the important role which occupational therapists can and do play in addressing the mental and physical health needs of older people, as well as their role in addressing the social determinants of health. The latter aspect of their role will help to manage future demands on services for older people.

8. The interaction between mental health conditions and long-term physical health conditions

8.1 Occupational therapists have always recognised the fundamental link between physical and mental health, and work to address both aspects, within the constraints of the services in which they work. COT would like to see this role recognised and supported in commissioning decisions. Examples of conditions for which occupational therapists address the psychological and cognitive aspects of long term physical conditions include rheumatologic conditions,266 limb amputation267 stroke268 acquired brain injury269 and progressive neurological conditions such as multiple sclerosis270 and Parkinson’s disease.271

8.2 The Mental Health Network publication, Investing in emotional and psychological wellbeing for patients with long term conditions provides many examples of the importance of addressing the mental health needs of people with long term physical health conditions.272 Many of the services mentioned are characterised by the ability to treat both the physical and psychological aspects of the condition and a multi-disciplinary approach to intervention, with teams including allied health professions such as occupational therapists, as well as physicians and clinical nurse specialists.

8.3 An example of a service which treats mental health issues arising from living with long term condition(s) is the Norfolk and Suffolk Wellbeing Service. Psychological Therapists and Psychological Wellbeing Practitioners use a CBT (cognitive behavioural therapy) based approach to treat anxiety and depression. Intervention includes delivering an eight week workshop specifically for those with anxiety and/or depression who are living with any diagnosed long term physical health condition.273

273 Rout, J. (2013). Norfolk and Suffolk Foundation Trust working with specifically with patients who have depression and/or anxiety as a result of living with their physical health difficulties. Case study. London: COT. Available at:- http://www.cot.co.uk/news/england/call-evidence-long-term-conditions-england Accessed 07/05/2013.
9. The extent to which patients are being offered personalised services (including evidence of their contribution to better outcomes)

9.1 The College would like to see services organised around a broad spectrum of conditions, over longer time frames, and using holistic approaches, in order for personalised care to be improved. These principles are illustrated in the example below:

9.2 Occupational therapists enabled K, a woman with learning disabilities and morbid obesity, to regain her independence. K was a 45 year old woman, living with her husband. She had a number of health and functional problems which had gone undetected, including morbid obesity (her weight was 33 stone), diabetes, respiratory failure and poor mobility. She remained in bed for 24 hours per day. OTs helped K by improving communication skills, goal setting, improving diet and exercise, and enabling mainstream health and social services to work more effectively with her. The outcome was that K lost 12 stone and is now able to manage her diabetes herself.274

ADDITIONAL COMMENTS

10. Defining long term conditions, in order to provide more effective management of interventions.

10.1 In order to provide more effective management for people with long term conditions, it may be useful to consider the definition of “health” rather than “long term condition”. The Ottawa Charter states that, “Health promotion is the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment.”275 Occupational therapists are well placed to promote health amongst people with long term conditions as their approach focuses on all three elements of health.

May 2013

Written evidence from the Royal College of Physicians of Edinburgh (LTC 47)

INTRODUCTION

Hospitals are seeing increasing number of medical admissions. The increase in numbers is multifactorial with demographic changes accounting for less than half of this rise.

As hospitals decrease their bed numbers, they must reduce their length of stay (LoS) to compensate. This LoS needs to drop even further due to increasing admissions. As a consequence of this, elderly patients may leave hospital with poorer functional capacity and fail in the community. This leads to re-admission and the creation of a vicious cycle that may ultimately lead to 24 hour care.

The key to assessment of the older person is the Comprehensive Geriatric Assessment (CGA) carried out by the multidisciplinary team including the consultant. Geriatricians are now one of the largest medical specialities in the UK and they provide significant input into acute GIM on call.

Over the last few years there has been a shift of resources from secondary care to primary care. A greater emphasis has been placed on preventative care in the community. However, there are challenges set in the most at risk population in primary care. These are:

(i) Multiple co-morbidity.
(ii) Polypharmacy.
(iii) Cognitive impairment/dementia.
(iv) Assessment of capacity.
(v) Legal and ethical issues.
(vi) Carer support.
(vii) Palliative and End of life care.

General practitioners have been set up to provide preventative care, with the creation of Quality Outcome Frameworks (QoFs). However, the evidence to say that QoFs have a significant effect in improving care is limited (Cochrane data base Sept 2011). Good primary care also involves the rational use of hospital based resources which is achieved through the GP gate keeping role. Unfortunately, the new GP contract and the loss of normal out of hours care means that for a significant part of the week an elderly person will not be looked after by their primary health care team.


Intermediate care (IC) was first described in the literature in 1985, and over the years many different models of intermediate care have been proposed/developed. The evidence for supporting intermediate care is variable and the studies are small, with different outcomes being looked at and with differing methodologies being used. Therefore this makes generalisable conclusions problematic in suggesting that intermediate care can be used to stem hospital admissions.

There is, however, clearly an opportunity to shift focus more into the community. Hospital clinics in all specialties are full of patients on long term follow up for “review and monitoring”. This can only be successful if there are clear pathways for patients and properly supportive networks across the care sectors.

Questions

1. There is little scope to vary the current service responsibilities so that more people are treated outside hospital. Significant changes would have to be made to primary care services ensuring better out of hours support. Geriatricians would have to have job plans modified to support intermediate care (IC) solutions with consequent reduction of their input to the acute medical take. To make IC most effective patients admitted to these beds must have full access to all investigations required. This may involve elderly patients requiring adequate transport facilities readily available to access the investigations. If more Geriatric Medical Specialists are involved in primary care dealing with these complex patients, then this has significant cost implications. It is possible that in several areas increasing service provision may be delivered in primary care and there is scope for reconfiguration. This has occurred, for example, in Diabetes but the experience is mixed. The evidence is that service quality may deteriorate with rising glycaemic control in patients discharged to primary care. The published evidence is that in the majority of studies HbA1c rises in patients discharged to GP care. In the best outcomes there is no difference between primary and secondary care outcomes but in no studies is there evidence of improved glycaemia in GP treated patients.

2. It is not felt that the present local primary NHS services are geared up to look after people with multiple co-morbidities including long term conditions. The primary health care team are used to dealing with single organ problems including practice nurses who have expertise in the management of, for example, asthma/COPD/diabetic clinics. There is, however, a need for primary care to consider how patients with frailty can be identified and monitored in the community. Social services will provide support for people with long term conditions by providing care packages. The carers who deliver this care, while good, often fail to recognise when their client is deteriorating and becoming frailer. Ultimately, a crisis occurs in the community leading to emergency admissions. To address these problems, the primary care team should have systems that recognise the development of frailty and ensure that those patients are reviewed frequently in the community. Similarly, carers for those people should be trained to look for changes and to seek help/advice at an early opportunity, thereby trying to prevent the crisis developing.

3. The new Clinical Commissioning Groups are in their infancy and discussions are taking place at local levels to support design of services. It will be important to embed strong primary and secondary clinician representation at Regional Commissioning Board and CCG level. It is important that significant resources should be available to facilitate the development of these new services otherwise they will never reduce avoidable hospital admissions.

4. In developing services, there is a great risk that care will become fragmented even for long term conditions. It is likely that cherry picking of some areas will occur. Geriatricians and social services have a long history of a team approach to patient care. It is important that this team ethos is sustained across all sectors of care delivery.

5. Obesity is a significant problem and one that is increasing in size! This problem needs to be addressed at a very early age in a child’s life. The education of the child (and parents), and need for regular exercise should be ingrained from an early age. This will involve major action from the government and should include adequate education on dietary intake. There is also a need to specify in which co-morbidities the management of obesity will occur. For example, obesity is relevant to IHD, hypertension and diabetes. The clinical issues relate to the severity of obesity with a need for initial dietary treatment, drug therapy and surgery in extreme cases and thus the issue is probably best approached as part of treatment for the key co-morbidity.

6. Stroke, heart failure, diabetes and palliative care services have been promoted as examples of integrated care. The last in particular could be a model for other disease processes. The hospital and community palliative care teams are a combined service with heightened access to social care streams. There is a common goal and a real effort made to provide a seamless service. In diabetes there are many long standing examples of integration but this has also resulted in deterioration in glycaemic control in some areas. Subsequent revision of protocols and the introduction of QOF targets improved matters. There remains concern, however, that these changes required incentivisation of primary care and an increase in costs. There are no examples as yet of which we are aware of successful integration of services across health and social care in England. Northern Ireland does operate a successful integrated service and it would be appropriate to seek advice from colleagues in Northern Ireland.

7. The effect of the ageing population with long term conditions could be catastrophic for the NHS as it stands. The secondary care services are struggling to cope, and this is emphasised during a flu crisis or norovirus outbreak. Appropriate primary care services supported by specialists (clinicians) in elderly care and allied
health care professionals should be developed to offset this. Patients who undergo a CGA are 25% more likely to be at home and alive 6 months later compared with those admitted and managed on other wards. Elderly people who are in 24 hour care often suffer from fragmented primary and secondary care services. A nursing home may have a number of GPs from different practices going in every day. Admission to secondary care for that older person may lead to placement on an inappropriate ward. Problems alluded to in the introduction [(i) to (vii)] are common in the nursing home patient. These problems require time and an empathic approach being taken by the clinician with the person and their family.

8. There is a major interaction between mental health and long term conditions both in the patient and their families. There is significant carer psychiatric morbidity in carers of stroke victims at three years post stroke. Studies have demonstrated that mental health/psychology support is beneficial for the management of long term medical problems. There is a significant lack of psychology support for people with mental health problems. Perhaps the re-allocation of non-proven therapies eg homeopathy to proven psychology therapies may help the situation.

9. In certain diseases patients are being offered personalised services. The stroke patient is discharged home with the stroke discharge team. He/she will receive input from the team for a period of time and when stable/recovered is passed to the generic support services if required. Similar teams have been set up for patients with fractured neck of femurs and COPD. Evidence from stroke demonstrates improved outcomes, shorter hospital stays and usually increased patient satisfaction. There are also trials of personal budgets of care. There is a widespread move to patient involvement in decision making—nephrology is notable. In addition, in this specialty the shared care dialysis programme encourages patients to “know their numbers” and contribute to their treatment (self weighing, opening packs, self needling, machine operation). There is evidence of better treatment compliance under this scheme. There is also a concern that disparate members of the care team can all provide the same level of care. There is some evidence that protocols can improve this. Personalised services will require greater time input and planning.

9 May 2013

Written evidence from Sue Ryder (LTC 48)

1. ABOUT SUE RYDER

1.2 Sue Ryder is a charitable provider of health and social care services across the UK. We provide specialist neurological and palliative care in a range of environments including community and home-based care delivery alongside our hospices and neurological care centres.

1.3 We care for people with long term and progressive neurological conditions including Parkinson’s disease (PD), Huntington’s disease (HD), multiple sclerosis (MS), and dementia; and sudden onset conditions like stroke and acquired brain injury. We also support those at the end of life with long term conditions including heart failure, renal failure, and Chronic Obstructive Pulmonary Disease.

1.4 We work across communities with patients, their families, commissioners, GPs and other health and social care professionals. We are funded through charitable donations, contracts with health commissioners and local authorities and revenue from our network of more than 400 shops across the UK.

2. OVERVIEW

2.1 We very much welcome the Committee’s inquiry into support for people with long term conditions. As a provider of specialist services we are becoming increasingly concerned about the system’s current capacity to support those with complex long term conditions.

2.2 To ensure people have access to coordinated and integrated care that improves their health and care outcomes, a system must be created that predicts and responds to people’s needs along the entire trajectory of their care pathway.

2.3 Due to the complexity around treating and managing a long term and progressive neurological condition there are certain aspects of the management of care that require specialist attention.

2.4 While not a common long term condition like diabetes, neurological conditions affect more than 10 million people in the UK, of which over 1 million are disabled by their conditions and over 350,000 people require help for most of their daily activities.276 With significant improvements that have been made in supporting people to manage their condition the number of people living with neurological conditions has risen.

2.5 In response to the area of the inquiry that seeks an assessment of the readiness of local NHS and social care services to treat patients with long-term conditions within the community we have highlighted some of our concerns and priorities to ensure the delivery of better care, and improvement of patient outcomes.

276 Neuro Numbers, 2003
3. Integration

3.1 For people living with long term and progressive neurological conditions that require specialist support, integration between health and social care services is vital to ensuring they have access to the right services at the right time. In some instances people can find themselves falling between the gaps between these services because of the lack of coordination and planning. This means they are not accessing the services they need nor achieving their desired health and care outcomes.

3.2 This was the case for one of our day service users with MS who lives in a housing association property where she moved to five years ago when her needs worsened. The progression of her condition since then has meant that she can no longer use the stairlift or wetroom upstairs and has been forced to convert her dining room into a bedroom. The only toilet is downstairs in an outhouse which is unsuitable. After an assessment from an occupational therapist it was recommended she have an extension. However neither the housing association or local authority could agree on who would pay for the adaptation. She has recently found out that neither party will pay and if she wants to live somewhere more suitable she will have to move again. This lack of coordination illustrates the tensions at a local level. Inappropriate planning between the local authority and housing association with little regard for and inclusion of health has meant that it is the service user that loses out, unsupported by a system that does not adequately meet her needs.

3.3 The opportunity for commissioners of health and care to collaborate in Health and Wellbeing Boards (HWBS) and develop a Joint Health and Wellbeing Strategy (JHWS) for the local community is a key step forward to ensuring the most appropriate services that meet an individual’s outcomes are designed.

3.4 The new HWBs provide the opportunity for integrated planning to be stimulated and a consistent approach adopted across the country. We hope they will establish the right mechanisms which will make integrated working a reality and improve the lives of people with complex long term needs and those at the end of life.

3.5 Many of the people Sue Ryder provides care for live with progressive neurological conditions such as multiple sclerosis, Huntington’s disease or Parkinson’s disease. These individuals will live in the care system for many years. Evidence collected for Sue Ryder indicates that these individuals benefit from services that address their specific needs resulting from their condition to help them to achieve their desired broad outcomes. The HWBs’ duty to deliver a JHWS for their local area will put in place a local strategy on which integrated commissioning to plan these appropriate services can be based. To do this JHWS must make a proper assessment of the needs of their local population and identify the needs of these condition specific groups. Data collection through the JSNA must be improved.

3.6 The JHWS will only be as robust as the data on which they are based. The strengthened role of the JSNA should mean that a more responsive system to condition specific local need is developed.

3.7 We are concerned that the preparations for the new system and implementation aren’t robust enough. Determining the needs of the local population and the tools that are needed to make this a reality will be central to developing integrated commissioning that improve health and care outcomes.

4. Data Collection and Service Planning

4.1 Sue Ryder recently ran a freedom of information request to local authorities in England asking about the specific design and delivery of services they offer for individuals with neurological conditions. These results have been compiled in to the report The Forgotten Millions. Responses were received from 131 local authorities. Only 5% of the local authorities surveyed were able to provide detailed data on the number of individuals with neurological conditions that they provided care services for. 72% of the authorities indicated that they do not collect detailed data categorising specific neurological conditions. 79% of local authorities indicated that they do not have a specific commissioning strategy for services for people with neurological conditions.277

4.2 The results, particularly the lack of data available to identify those living with neurological conditions in local communities is concerning. Because local authorities are not collecting this data they don’t know the number or range of neurological conditions that people in their communities are living with and therefore limited in their capacity to plan services accordingly. As a result it is likely that many of these individuals are not receiving the best services for their needs which will impact on their health. It is telling that only 10% of local authorities have a strategy in place for people with neurological conditions. This evidence indicates that the initial needs assessment is crucial in determining the strategies and the shape of future services.

5. Care Coordination

5.1 Individuals with a long term and progressive neurological condition require specialist support from a multidisciplinary team including specialist nurses, physiotherapist, occupational therapist, speech and language therapist. The fluctuating nature of their condition and speed at which their condition changes means they need timely access to specialist services responsive to their needs.

277 Sue Ryder, The Forgotten Millions, November 2012
5.2 A multidisciplinary team approach enables the development of tailored care plans to support patients on a long term basis after their diagnosis. This approach means their care can be anticipated, so they are less likely to reach a crisis point needing emergency care. However, it is concerning that more than a quarter of people with Parkinson’s have never spoken to a PD nurse specialist.

5.3 Individuals with a long term neurological condition should have access to a neurology specific nurse and/or coordinator. The role of a specialist coordinator and nurse is essential in providing timely access to help with symptom management, planned and anticipated care, and giving support to individuals in understanding their condition.

5.4 We have heard of instances where specialist nursing roles are not being replaced due to limited resources. In one case we are aware of posts being replaced by general nurses who don’t have the expertise to manage someone with a complex neurological condition. As a result individuals are not getting the care and support they need from experienced specialists.

MND patient said: “MND is such a lonely disease—even when you are surrounded with family and friends and doctors and nurses who are absolutely brilliant, you can still feel alone. Having someone on hand to talk to who really understands what the illness means and how it will develop and affect my life is really helpful. Sometimes you just want someone to be there who can advise on the practicalities of living with MND, who can understand what’s coming at me in the future and put forward my point of view on the care I want.

“When things aren’t going so well, it will be nice to have someone down to earth to rely on as a day-to-day support mechanism to talk about what’s happening to me and to give me the encouragement I need to keep living with a long-term illness.”

5.6 Joint working between local authorities and clinical commissioning groups has to be encouraged in order to deliver care that fits around the needs of individuals.

5.7 When care is not coordinated it is likely that service users will fall between the gaps in the system. Unsupported in this way they can lack an understanding of their choices and entitlements, become isolated and unable to access the care they need. This can lead to their health deteriorating faster than necessary and potentially ending up in hospital in an emergency admission.

5.8 In 2009–10 14% of people with Parkinson’s disease, MS and MND that were discharged from hospital after an overnight stay were readmitted within 28 days as an emergency. There has also been a 32% increase in emergency admissions to hospital for this group. This indicates a failing of the system to anticipate people’s needs, support people in the community, and a lack of continuity of care.

6. SELF-MANAGEMENT AND PREVENTION

6.1 More common long term conditions such as diabetes can be prevented by making better personal lifestyle choices and staying healthy. Progressive neurological conditions such as MS, MND, HD and PD cannot. Secondary prevention therefore is vital in making sure those with existing complex long term conditions like COPD and progressive neurological conditions such as those listed don’t deteriorate faster, are kept out of hospital and have an improved quality of life. Services such as specialist community programmes support those already living with a long term condition with a combination of practical advice and planned activity to help them manage their condition, whilst remaining active in their community.

Sue Ryder Manorlands hospice—respiratory programme

A Sue Ryder hospice runs a respiratory programme that offers practical and emotional support to help people manage their condition. Breathing exercises are followed by education sessions including how to help breathing, dietary advice, pacing and fatigue management, and what to do if things get worse. The service increases people’s confidence, improves and manages their symptoms and supports them to develop a personal care plan. A respiratory group offers advice on monitoring and improving breathing difficulties. Breathing recovery postcards have also been developed for the community to offer advice at home. Information and support such as this should be available to individuals within the community, as well as in healthcare settings such as hospitals and GP surgeries.

6.2 Health and wellbeing boards must consider the importance of secondary prevention in their health and wellbeing strategies. These play a vital role in helping to improve the wellbeing for those with long term conditions. Commissioner must accordingly make adequate provision for specialist day services such as the respiratory programme that integrate health and care support.

7. DESIGNING PERSON CENTRED SERVICES

7.1 Designing innovative services that are tailored to the needs of individuals is at the heart of Sue Ryder’s vision. Person centred care drives the development of our service delivery. We fully endorse the principle of
personalisation where it improves service user outcomes. We supported the development of Demos’ report Tailor Made\textsuperscript{281} which explored personalisation and what it means for people with complex and long term needs.

7.2 We believe in giving people meaningful choice and control; this has to be supported by availability and access to information, advice and advocacy at the right time, and in the right format to enable people to plan and make decisions about their care.

7.3 The success of making sure people have choice and control over their care will depend on the quality and variety of local services available to them, and support available to access them.

7.4 The Tailor Made report raised some particularly poignant policy issues in regards to person centred care for people with long term and progressive neurological conditions. It argued that the personalisation agenda needs to be expanded, and the rhetoric to reach beyond personal budgets.

7.5 The outcomes that individuals identified as being important were: remaining independent; having a job or volunteering; maintaining links with their family; and being with people they know. In order to achieve these, multiple services must work together.

7.6 Although we see personal budgets, and direct payments in particular, as a tool to empower people to have more control over their care they may not be enough to achieve multi-service integration and deliver the outcomes people want.\textsuperscript{282} We believe that for control over individual care to be meaningful there must be a vibrant market place of multiple services which people can to choose to purchase from.

7.7 Health and care commissioners need to work with providers to ensure they are able to respond to local needs and encourage the development of a marketplace that meets the needs of the local population. In turn packages of care need to be developed by CCGs, local authorities, providers, service users and their families that support individuals to access person centred universal services.

7.8 There should be provision within the JHWS to include a local strategy for the health and wellbeing of those in their area living with a neurological condition. With their role to coordinate health and social care, HWBs and their responsibility to develop JHWS, will be key to delivering a strategic commissioning framework that includes the opportunity to pool resources and plan integrated services to deliver improved user outcomes.

8. EDUCATION AND TRAINING

8.1 Given the complex nature of some long term and progressive neurological conditions, it is essential that generalist health and care professionals are appropriately trained in neurology and managing symptoms appropriately.

8.2 We hear from staff across our neurological care centres that the knowledge of general health professionals in neurological conditions can be limited. A member of staff in one of our care centres often accompanies a resident on a hospital visit to make sure the hospital manage their condition appropriately. We have developed a hospital passport to ensure that on admission staff have all the information they need in order to manage the resident’s care in the best way according to their needs and preferences. We would like this practice to be encouraged in all care settings.

8.3 One of Sue Ryder’s strategic aims is to share best practice and knowledge in providing specialist care for neurological conditions. We have education programmes in our centres that continue to drive up quality internally but share good practice in managing complex neurological conditions across the locality. A student nurse mentoring programme at our centre Hertfordshire is also helping to raise the profile and understanding of neurological conditions in everyday practice.

9. LONG TERM CONDITIONS AND END OF LIFE CARE

9.1 The system currently does not make adequate provision for end of life care for those with long term conditions, including neurological, COPD and heart failure. End of life care should be a central part of the care pathway of long term conditions.

9.2 The recent end of life locality registers evaluation found that one of the biggest challenges in end of life care is ensuring that non-cancer patients with terminal disease have access to the same level of services as cancer patients, with the choice to die at home if they wish.\textsuperscript{283} It is essential therefore that these patients, including those with complex long term conditions like COPD and neurological conditions are added to the register.

9.3 Specialist nurses and multidisciplinary teams should play a vital role in encouraging the identification and recognition of those with long term conditions who are at the end of life.

9.4 We have found that our hospices are coming up against challenges with COPD patients. COPD is a long term and terminal condition. Although COPD patients can be sick for a number of years many don’t believe

\textsuperscript{281} Tailor Made, Demos, 2011.
\textsuperscript{282} Tailor Made, Demos, 2011.
\textsuperscript{283} Ipsos Mori, End of Life Locality Registers evaluation Final report (June 2011) p.143.
or are aware that they have a terminal illness. As a result many don’t have an Advance Care Plan in place by the time they come in contact with the hospice, nor have they had conversations about the trajectory of their condition with a health care professional. We have experienced the same for our neurological patients. Patients therefore can find it very distressing and daunting to discover how ill they are when they are referred to the hospice. When they come to the hospice they are supported to understand and manage their condition and to develop an Advance Care Plan.

9.5 Palliative care is different for people with long term conditions. Staff and services need extra equipment and training. Referrals need to be much more timely and more needs to be done on educating health professionals on better understanding and communication of conditions.

9 May 2013

Written evidence from Vertex Pharmaceuticals UK (LTC 50)

1. SUMMARY

1.1 Vertex’s product Kalydeco (ivacaftor) is the first in a new class of innovative medicines that treats the underlying causes of cystic fibrosis, a genetic disease affecting approximately 10,000 people in the UK.

1.2 Kalydeco has been available to all patients with the G551D mutation in England since 1st January 2013. This has a number of implications for the commissioning and delivery of specialised services for cystic fibrosis, particularly in relation to NICE’s appraisal process for Highly Specialised Technologies and NHS England’s clinical commissioning policies for higher-cost medicines.

2. ABOUT VERTEX

2.1 Vertex is a global health sciences company that aims to accelerate the discovery, development, and commercialisation of critical medicines for life-threatening diseases including cystic fibrosis, hepatitis C, and epilepsy.

2.2 In 1998, Vertex established its first global research and development site in the UK. Researchers at Vertex’s approximately 150-person UK site are focused on discovering new medicines for a variety of cancer types and neuroinflammatory diseases.

3. ABOUT CYSTIC FIBROSIS

3.1 Cystic fibrosis is a genetic disease affecting approximately 10,000 people in the UK. It is a complex and multi-system disease that causes the internal organs, particularly the lungs and digestive system, to produce thick sticky mucus that eventually leads to death from respiratory failure. In 2011 the median age at death for cystic fibrosis patients was 26 years.284

3.2 Cystic fibrosis is also associated with other long-term conditions including diabetes, infertility, and osteoporosis.285

3.3 The care of children and adults with cystic fibrosis is coordinated by specialised services that are directly commissioned by NHS England. These specialised services provide care from a multidisciplinary team including specialist doctors, nurses, and allied health professionals.

4. KALYDECO (IVACAFTOR) FOR CYSTIC FIBROSIS

4.1 Vertex’s product Kalydeco received regulatory approval for the treatment of cystic fibrosis in patients aged six years and older who have a G551D mutation in the cystic fibrosis transmembrane conductance regulator (CFTR) gene from the European Medicines Agency in July 2012.

4.2 In 2011 there were 466 cystic fibrosis patients with a copy of this mutation in UK.286 Due to this small patient population Kalydeco is widely recognised as an ultra-orphan medicine (ie a treatment for a very rare disease).

4.3 Kalydeco is the first in a new class of innovative medicines that treats the underlying causes of cystic fibrosis. The results of clinical trials indicate that treatment with Kalydeco could lead to a 10-year increase in life-expectancy and a significant improvement in quality of life.

4.4 Kalydeco has been available to all patients with the G551D mutation in England since 1st January 2013 following a commissioning decision made by the Clinical Priorities Advisory Group. Since 1st April 2013 it has been commissioned on a national basis by NHS England.


5. NHS POLICY ISSUES

5.1 UK clinicians have noted that Kalydeco “is life changing for the few patients with cystic fibrosis for whom it is indicated” and, as the first medicine of its kind, “has the potential to transform cystic fibrosis care”.\(^{287}\) This transformation in cystic fibrosis care may require changes to the way that specialised services and treatments for the disease are commissioned and delivered.

National Institute for Health and Care Excellence

5.2 The National Institute for Health and Care Excellence (NICE) assumed responsibility for the appraisal of Highly Specialised Technologies (ie ultra-orphan medicines) on 1st April 2013. It is essential that NICE’s appraisal process for Highly Specialised Technologies recognises the value of innovative medicines for the treatment of very rare clinical subsets of more common diseases, particularly long-term conditions for which there is no cure, and takes this into account when making its recommendations.

NHS England

5.3 Although the majority of medicines for the treatment of cystic fibrosis are funded using the Payment by Results system, certain higher-cost medicines are directly commissioned by NHS England. It is essential that this direct commissioning continues to ensure cystic fibrosis patients have equitable access to higher-cost medicines across England.

5.4 If Kalydeco and other innovative new medicine for cystic fibrosis lead to a reduction in exacerbations and hospital admissions, it may be possible to redesign some services to allow patients to receive a larger proportion of their care in the community. This would be likely to lead to further improvements to patients’ quality of life and reduce the costs of providing specialist services in a hospital setting.

9 May 2013

Written evidence from Astellas Pharma Ltd (LTC 51)

SUMMARY

— Lower urinary tract symptoms (LUTS) including urinary incontinence are not simply a natural consequence of ageing. With high quality advice and support, and early access to the right interventions, most conditions are manageable.
— Failure to secure a prompt diagnosis and appropriate treatment for continence problems can have a significant societal impact and downstream costs for NHS services.
— An ageing population means more people living with long-term health conditions (LTCs), such as LUTS, will have a significant impact on the demands placed on adult social care and health services.
— Care for patients with LUTS takes place across different NHS and social care settings, it is therefore imperative that they are able to access fully integrated services throughout the whole patient pathway.
— Despite the existence of clinical guidelines on provision of effective continence services, there is evidence of gaps and variations in the quality of care available to patients across England.
— Health and social care quality standards for LUTS and continence will provide useful tools for commissioners and providers when designing and monitoring performance of their local continence services.
— To deliver consistent improvements in continence care, these quality standards must be closely aligned and translated into key levers and mechanisms within the NHS and social care quality improvement framework.

1. INTRODUCTION

1.1 Astellas Pharma Ltd (“Astellas”) welcomes the opportunity to respond to the Health Select Committee’s inquiry into the management of LTCs. Astellas is committed to working in partnership with health and social care services in England to deliver high quality, integrated care, and support the best possible outcomes for patients.

1.2 The content of our submission focuses on the experiences and insights from our urology business where we have been working with patient, clinical and NHS partners over a number of years to build consensus on the core components of high quality care for patients with LUTS including urinary incontinence.

2. SUPPORTING PEOPLE TO MANAGE THEIR SYMPTOMS

2.1 LUTS cover a diverse range of conditions from the relatively mild to more severe and debilitating and it is estimated that the prevalence of at least some form of LUTS will be almost two in every three adults.288 These symptoms can have a significant impact on quality of life with the potential to negatively affect an individual’s mobility, their sleep, their ability to carry out day-to-day activities as well as their mental wellbeing.289,290

2.2 It is important to know that LUTS are not simply a natural consequence of ageing. With high quality advice and support, and early access to the right interventions, most conditions are manageable.291 Unfortunately, many continence problems are left undiagnosed, partly because individuals are often too embarrassed to come forward and seek help.292 Failure to secure a prompt diagnosis and appropriate treatment for continence problems can lead to poorer outcomes for patients, and escalating care costs through increased morbidity and mortality, for example through the possible heightened risk of falls and fractures amongst older people.293 Unnecessary catheterisation and associated urinary tract infections, pressure ulcers linked to poor continence care and acute hospitalisations.294

2.3 Providing high quality continence care and support is a key test of the capacity of the health and social care system to uphold every patient’s right to dignity and respect. With an ageing population, the number of people affected across England is set to rise—the need to address the current variations in quality of care provision is increasingly pressing.

3. TREATMENT IN COMMUNITY SETTINGS AND INTEGRATED CARE

3.1 Care for patients with LUTS takes place across different NHS and social care settings, it is therefore imperative that they are able to access fully integrated services. A fully integrated continence service should deliver joined-up, patient-centred care throughout the whole patient pathway across NHS and social care settings.

3.2 Practical guidance for commissioners and providers on developing an integrated continence service was set out by the Department of Health in Good Practice in Continence Services295 in 2000, and reinforced in the National Service Framework for Older People.296 Published in 2001. However, despite the existence of these resources, evidence from the National Audit of Continence Care published by the Royal College of Physicians during 2010 revealed worrying gaps and variations in the standards of care available to patients and a lack of local designated leadership in local services.297

— Whilst 55–80% of continence services reported themselves as integrated across healthcare settings, only 4 could fulfil all the criteria listed in Good Practice in Continence Services.

— Fewer than half of all hospitals (48%) and primary care continence services (40%)—which chose to describe themselves as providers of integrated care—could identify a Director of Continence Services in their area.

— Commissioning typically occurs in “block contracts” for urology and gynaecology continence services, rather than adopting a partnership approach between providers and across settings. In addition, there is little evidence of users being involved in planning or evaluation of services.

— Structured training on continence care occurs in fewer than half of hospitals (49%) and mental health care sites (39%).

3.3 The lack of designated local leads responsible for coordinating services coupled with patchy implementation of best practice guidelines has led to the majority of continence services being poorly integrated across acute, medical, surgical, primary, care home and community settings.298 Widespread under-prioritisation has resulted in disjointed care, sub-optimal patient outcomes and downstream costs associated with poor care. The NHS reforms provide an opportunity to address these shortcomings and appropriate services are in place to reflect the prevalence of LUTS.

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290 Irwin DE, Milson I, Reilly K, et al., Men and women with overactive bladder symptoms report higher prevalence of depression and lower quality of life: results from the EPIC study, Abstract, ICS 2006
291 Department of Health, Good practice in Continence Services, April 2000
295 Department of Health, National Service Framework for Older People, March 2001
296 HQIP/Royal College of Physicians, National Audit of Continence Care, September 2010
297 HQIP/Royal College of Physicians, National Audit of Continence Care: Combined Organisational and Clinical Report, September 2010
3.4 In the new NHS structures, health and wellbeing boards (HWBs) will have a key role in addressing the fragmented nature of continence services in England. Bringing together the experiences and perspectives of representatives from across local authorities, the NHS and patient and public representatives, HWBs are well placed to provide the necessary strategic oversight required to ensure integrated services are designed to reflect the needs of the local health population and scrutinise how effectively these services are being delivered.

4. SUPPORTING COMMISSIONERS

4.1 The recent NHS reforms provide a clear opportunity to address these poor practices and focus on improving outcomes for people affected by LUTS. A key part of the new NHS quality improvement framework is the introduction of quality standards, prepared by the National Institute for Health and Care Excellence (NICE), which describe markers of high quality care that, when delivered collectively, should improve the effectiveness, safety and experience of care for people with a particular condition.

4.2 Astellas welcomes NICE’s plans to develop quality standards for LUTS in men and urinary incontinence in women which will provide a set of concise statements designed to drive quality improvements across a pathway of care. These will provide useful tools for commissioners and providers when designing and monitoring performance of their local continence services. To succeed, we believe that the final set of statements and supporting metrics should focus on those approaches and interventions that will ultimately make the most difference in terms of patient outcomes, including increased symptom awareness, earlier identification of symptoms and timely access to the best possible quality treatment and supportive care.

4.3 As part of its expanded remit, NICE now also has responsibility for developing guidance and quality standards in social care. Encouragingly, NICE is considering developing a social care quality standard on promoting continence and preventing and managing incontinence in adults in care homes and the community. It is important that any supporting statements and metrics for social care are closely aligned with those included in health quality standards to ensure consistency in the provision of care across both settings.

4.4 To embed high quality care continence care throughout the health and social care system, quality standards for both health and social care must be translated into key levers and mechanisms within the NHS Outcomes Framework, NHS Adult Social Care Outcomes Framework and the clinical commissioning group outcome indicator set (CCGOIS).

5. IMPACT OF AN AGEING POPULATION

5.1 Astellas supports the Committee’s focus on the capacity of social care services to treat patients with long-term conditions, such as LUTS, in the community. The prevalence of LUTS amongst the over 65s is higher than in the general population, and of the thousands of people entering the social care system each year, a large proportion will be experiencing some form of continence problems—faecal and urinary incontinence has been cited as the second most common reason for people being admitted to residential and nursing homes.299

5.2 There is widespread recognition that an ageing population means more people living with long-term health conditions, including LUTS, will have a significant impact on the demands placed on adult social care and health services.300 Social care services must work closely with health services to ensure that service users receive the treatment and support they need to manage their condition effectively and prevent complications which will result in unplanned hospital admissions.

5.3 The Care Quality Commission’s Health care in care homes: A special review of the provision of health care to those in care homes, which looked at how well the health care needs of people living in care homes were met, based on commissioning and provider behaviours, found worrying gaps in the provision of personalised care, treatment and support for social care service users:301

— 25% of residents with continence needs felt that they did not have a choice of male or female staff to help them use the toilet.
— Most homes (85% of nursing homes and 78% of residential homes) included in the review provided residents with information on continence care, although a third of residents reported that they did not feel that they were offered choices about how their continence needs are managed.
— Across all care homes, just 36% of staff confirmed that they had attended training about continence care in the last 12 months.

5.4 A quality standard on “promoting continence and managing incontinence” featured within the long-list of social care quality standards recently proposed by the Department of Health, to be developed by NICE. A social care quality standard on continence problems would support commissioners and providers in assessing how they identify and monitor symptoms, how they support patients with continence needs, and deliver appropriate staff training. Astellas therefore believes that a quality standard on incontinence has the potential to significantly improve the standards of care identified in the Care Quality Commission’s report, and has a key role to play in supporting the delivery of high quality continence care in social care settings.

299 Department of Health, Good practice in Continence Services, April 2000
300 House of Lords Select Committee on Public Service and Demographic Change, Ready for Ageing?, March 2013
301 Care Quality Commission, Health care in care homes: A special review of the provision of health care to those in care homes, March 2012
6. About Astellas

6.1 Astellas is a research and development-driven global pharmaceutical company that develops and markets clinically effective therapies for a number of therapy areas where there is an unmet clinical need including urology, oncology, dermatology, anti-infectives, pain and transplantation. The European and UK operations are based in Chertsey, Surrey and the company has a UK workforce of over 250.

9 May 2013

Written evidence from Macmillan Cancer Support (LTC 52)

Executive Summary

— Cancer is a long-term condition for those who are dealing with long-term physical and emotional effects from cancer and its treatment. As such, it should be included with the scope of the Inquiry.

— The NHS and social care system in England must have a greater focus on the long-term consequences of having cancer. In particular, NHS England must ensure that the new arrangements for commissioning are driving the redesign of aftercare to support survivorship. This includes taking forward the recent recommendations of the National Cancer Survivorship Initiative.

— Our evidence suggests that people with long-term conditions can manage their condition appropriately when they have the right opportunities, resources and support. They need information, help with shared decision making, good care coordination, support with self management, and rapid access to clinical expertise if required. These requirements are also common to people affected by cancer.

— People’s wellbeing will be greater if they get the personalised support that they need. An example of this is the “Recovery Package” which promotes: effective assessment and care planning, good communication through a “Treatment Summary” and offers education and support events (Health and Wellbeing Clinics) which inform patients about how to take care of themselves, what to look out for and who to contact if needed.

— Effective service provision for people with long-term conditions should include return to work support. This includes ensuring that the NHS is better incentivised to promote work as a positive health outcome for people with long-term conditions, and action to address the gap in vocational rehabilitation provision. We would also like health and wellbeing boards and joint strategic needs assessments to highlight and take action to address work support needs.

1. Introduction

1.1 Macmillan welcomes the opportunity to respond to the Health Select Committee’s inquiry on the management of long-term conditions.

1.2 Cancer is a debilitating disease and the effects of cancer can be felt a long time after treatment has ended. The National Cancer Survivorship Initiative (NCSI) is a partnership between the Department of Health and Macmillan Cancer Support, supported by NHS Improvement, which originated from the Cancer Reform Strategy (2007). As a result of work of the NCSI, the long-term consequences of cancer and its treatment are now better understood. In addition, new approaches to meeting the needs of cancer survivors have been tested.

1.3 The NCSI’s work provides a strong evidence base for cancer to be considered as a long-term condition. As such, we were surprised that cancer was not included in the definition of long-term conditions set out by the Inquiry (although we note that the Committee cites a Department of Health (DH) definition).

1.4 Our response to the Inquiry therefore begins with our rationale as to why cancer should be treated as a long-term condition. The rest of our response focuses on the importance of supporting people with long-term conditions during and after treatment has ended, and the importance of supporting people back into work.

2. Cancer as a Long-term Condition

2.1 Cancer is a long-term condition for those who are dealing with long-term physical and emotional effects from cancer and its treatment. We strongly encourage the Committee to consider cancer in its review of the definition of long-term conditions.

2.2 Around 1.8 million people in England are currently living with cancer. This number is increasing by over 3% a year and the total figure will rise to over three million by 2030.\(^{302}\) One reason this figure is rising is that many more people with cancer are surviving, thanks to improved screening, earlier diagnosis and new treatments. Whilst it is extremely positive that more people with cancer are surviving, for many, the end of treatment is the start of poor physical or emotional health that can continue for years.

2.3 It is estimated that around 20–25% of people treated for cancer are currently experiencing a consequence of cancer and its treatment which has an adverse impact on the quality of their life.\textsuperscript{303} The physical problems people with cancer develop as a consequence of cancer treatment vary according to whether they have received radiotherapy, chemotherapy or have undergone surgery. Some are worst in the first few months or years after treatment and may improve over time. However, other problems will not appear for years. In addition to these physical problems, emotional problems such as depression are common.

2.4 Many cancer survivors live with other long-term conditions, either as independent co-morbidities, or caused by their cancer or treatment. For example, in the long term, people who have had chemotherapy may develop serious conditions such as osteoporosis, heart disease and even second malignancies, such as leukaemia.

3. Living with and beyond Cancer—Survivorship

3.1 The growing number of cancer survivors brings additional challenges in terms of understanding needs and how NHS and social care services can best support them.

3.2 In England, the NCSI was launched in 2007, at a time when most of the focus in terms of improving cancer services was on the diagnosis and treatment of cancer. In contrast, one of the main aims of the NCSI was to develop services to support and enable cancer survivors to live as healthy and as good a quality of life for as long as possible.

3.3 Before the NCSI, there had been very little research on cancer survivors. However, we now know more about the needs of cancer survivors than ever before. In particular, we now have cancer survivorship figures at a population level, at a patient level and at a health service level. Data at the population level is vital to help with planning the levels of services needed at any point in the cancer care pathway.

3.4 Evidence shows that many of these cancer survivors have unmet needs, particularly at the end of treatment, whilst others are struggling with consequences of treatment that could be either avoided or managed.

Improving outcomes for cancer survivors

3.5 High quality cancer survivorship can improve outcomes in all domains of the NHS Outcomes Framework. However, it can also contribute to improved outcomes within the Public Health Outcomes Framework—for example, reducing people’s risk factors for developing other conditions—and the Social Care Outcomes Framework—for example, through promoting independence.

3.6 The NCSI recently published Living with and beyond cancer: taking actions to improve outcomes.\textsuperscript{304} This set out a framework for survivorship outlining the action needed at five key stages of the pathway:

- Information and support from the point of diagnosis.
- Promoting recovery.
- Sustaining recovery.
- Managing the consequences of treatment.
- Supporting people with active and advanced disease.

3.7 The document sets out what has been learnt on survivorship, including interventions to meet needs that have been tested and ready to spread across England.

3.8 Underpinning the recommendations in the report is the need to increase understanding and promote a cultural shift in professionals towards shared decision making and supporting patient self-management.

3.9 Macmillan encourages NHS England to take forward the recommendations outlined in this report—aimed at commissioners and providers—to ensure that outcomes are improved for cancer survivors. It is vital that the new commissioning arrangements drive forward the redesign of aftercare to support survivorship.

Information and support from the point of diagnosis

3.10 All patients and their carers with a long-term condition, regardless of its complexity, should be offered the opportunity and relevant information to help them develop a personalised self-management plan with a trained professional or peer, which is integrated into the formal care planning process.

3.11 Early cancer rehabilitation is also important: it can prevent avoidable ill health and is more effective when provided early to avoid conditions becoming more complex and costly to treat later on.

3.12 People with long-term conditions, including cancer, should also be offered support in considering work and education options at an early stage. This is discussed further in Section 4.


\textsuperscript{304} Supra note 1.
Promoting recovery

3.13 People’s health, wellbeing and overall quality of life will be greater if they get the personalised support that they need.

3.14 The case for the “Recovery Package” is set out in detail in the NCSI report. The Recovery Package promotes: effective assessment and care planning, good communication through a “Treatment Summary” and offers education and support events (Health and Wellbeing Clinics) which inform patients about how to take care of themselves, what to look out for and who to contact if needed. These components are similar across long-term conditions.

3.15 Providing support and education to facilitate effective self-management where desired can have a number of benefits for the individual and the system. Individuals undergoing structured self-management programmes report improved health literacy and health behaviours, increased confidence in their ability to navigate the health system, better physical functioning and a greater understanding of the appropriate services available.

Managing the consequences of treatment

3.16 Treatment for cancer, although vastly improving and expertly administered, can still have consequences that impact hugely on the ability of people to live meaningful lives. The recent 2012 DH Patient Reported Outcomes Measures (PROMs) survey highlighted some of these issues. For example, 38% of prostate cancer survivors reported urinary leakage and 58% reported impotence, and one in five colorectal survivors reported difficulty in bowel control.\(^{305}\)

3.17 Failure to manage the consequences of treatment can have a significant impact on patients and the system. Access to support for common health related problems caused by treatment should be routinely available and information should be given to people. Some services for intermediate or rare types of consequences may need to be commissioned through specialised commissioning. In all cases, some key principles should be followed: preventing or minimising consequences through healthier lifestyle choices and better treatment, informing patients of potential consequences, identifying patients at potential risk, assessing people through holistic needs assessments and supporting people through local care pathways.

Sustaining recovery

3.18 Physical activity has been proven to be impactful on the management of long-term conditions associated with cancer and its treatment, as well as reducing the possibility of recurrence of some cancers. We recommend that the DH “Let’s get Moving” pathway is routinely incorporated within cancer care pathways, and that “exercise on referral” schemes criteria explicitly include cancer.

Rehabilitation

3.19 The importance of rehabilitation to the recovery of people with long-term conditions is increasingly well understood and supports the NCSI’s work.

3.20 As more and more people survive and now live with cancer, early intervention and continuing access to rehabilitation can minimise the often predictable effects of lengthy treatment and the level of disability resulting from the disease itself. Closer integration between health and social care is also required to deliver excellent care and rehabilitation to people living with complex health needs.

3.21 Without effective rehabilitation, at all stages of the care pathway, the benefit of treatment will be limited and the health outcomes will be diminished.

3.22 Rehabilitation programmes are applicable across long-term conditions, and it is important that they include vocational rehabilitation support (which is covered in more detail in section 4). The National Cancer Action Team recently published recommendations on rehabilitation, including work, for commissioners and providers.\(^{306}\)

4. Difficulties Staying in or Returning to Work

4.1 Cancer, like other long-term conditions, can affect many aspects of a person’s life, such as their ability to work. In the Mandate to NHS England, the Government made it clear that it expects progress in supporting people with long-term conditions, including cancer survivors, and in particular for them to remain in, or find work.

Incentivising the NHS to promote work as a positive health outcome

4.8 It is essential that health professionals understand that work can help improve an individual’s health and well-being, and that they have an important role in helping people with long-term conditions, including cancer,


make informed decisions about their working lives. Macmillan recommends that health professionals start routinely talking to patients about the impact of cancer treatment on their ability to work—in particular, raising the issue of work early in the patient’s journey and signposting to further support where appropriate. The NCSI has produced guidance for health professionals on achieving positive health outcomes.307

Specialist vocational rehabilitation support

4.12 However, there is a severe lack of appropriate vocational rehabilitation services in the UK for people with long-term conditions, including cancer. Macmillan recently published a report Making the shift: providing specialist work support to people with cancer on the need to fill this gap in provision.308

4.14 Currently, NHS rehabilitation services, such as occupational therapists, tend to focus on hospital discharge only and lack the capacity to provide vocational rehabilitation. Government back-to-work programmes are more focused on supporting people on long-term benefits than people on sickness absence looking to return to work. Finally, occupational health (OH) service and private healthcare providers usually only provide vocational rehabilitation services to people working in large organisations and not all OH professionals are trained to provide advice on cancer.

4.2 There are 600,000 people of working age living with cancer in England.309 Around 100,000 new cases of cancer are diagnosed in people of working age each year in England.310 This means that, on average, there will be around 550 patients per provider per year for whom returning to work will be a consideration.

4.3 Work is an important part of helping people get back to normality after a cancer diagnosis and treatment. It has many other benefits, such as improving confidence and self-esteem, and it contributes to financial independence and material comfort. There is strong evidence to suggest that for people who experience ill health or disability, remaining in or returning to work can actually help promote recovery and rehabilitation, and lead to better quality of life and health outcomes.311

4.4 Supporting people with cancer, and other long-term conditions, is also good for the economy. In 2008, Policy Exchange estimated that £5.3 billion in productivity was lost that year as a result of cancer survivors not returning to work.312 As the number of people living with cancer is set to double over the next 20 years, this loss to the economy is likely to increase.

4.5 Research shows that the majority of people who are working when they are diagnosed with cancer want to return to work when they are ready and able to, or they need to for financial reasons.313 However, this can be difficult because people struggle with the consequences of cancer, such as fatigue and depression. Research also shows that people who have had a cancer diagnosis are 1.4 times more likely to be unemployed than those who have not.314

4.6 The main barriers that prevent people living with cancer remaining in or returning to work are threefold: a lack of support from health professionals on working during cancer treatment or returning to work after treatment; a lack of support from employers; and a lack of specialist vocational rehabilitation support.

4.7 Many people with cancer who are considering remaining at work, returning to their job or leaving it are given little or no information and advice from health professionals about the impact cancer can have on their working lives. Statistically, over half of people with cancer (60%) who were in work at the point of diagnosis were not informed by a health professional about the impact their cancer diagnosis might have on their working lives.315

4.9 Macmillan wants the DH and NHS England to pay greater attention to the role the NHS could play in helping more people get back to work. 4.10 It is also important that the health and social care systems work more effectively together. We would like health and wellbeing boards and joint strategic needs assessments to highlight and take action to address work support needs.

4.11 Another key barrier is the lack of specialist vocational rehabilitation services for people with complex problems who should be referred to a vocational rehabilitation service for specialist support.

310 Working age estimates are for 18–64 years, assuming 1% of people living with cancer are under 18.
313 Policy Exchange Research Note. The Cost of Cancer. February 2010
314 Macmillan Cancer Support/MORI. Working with cancer—A survey of people with cancer. 2001. 70% of respondents felt it was “very important” to continue to work, with a further 13% thinking it was fairly important
4.13 A large government-funded review of vocational rehabilitation in the UK found that structured vocational rehabilitation interventions can be both beneficial to individuals and cost effective. However, since this review there has been little progress at a national level. In particular there is still a lack of capacity to deliver effective vocational rehabilitation for people with long-term conditions.

4.15 To address the lack of specialist vocational rehabilitation services in the UK, Macmillan, as part of the NCSI, piloted a new model of vocational rehabilitation services for people with cancer. The evaluation of the pilots demonstrates that timely vocational rehabilitation interventions result in better work and health outcomes for people with cancer, and that they can be cost effective. Our work in this area also demonstrates that effective vocational rehabilitation for people with long-term conditions, including cancer, requires a combination of healthcare and workplace interventions.

4.16 Our report makes a number of recommendations to Governments across the UK. In particular, we have called on Governments to take responsibility for improving access to and the availability of vocational rehabilitation, and coordinating health and workplace support. We would like the Government and NHS England to provide more encouragement to NHS commissioners to invest in vocational rehabilitation support for people with long-term conditions, including cancer.

9 May 2013

Written evidence from Alliance Boots (LTC 53)

About Alliance Boots

Alliance Boots is a leading international pharmacy-led health and beauty group, employing over 70,000 people in the UK. The group’s businesses in the UK include the Boots pharmacy chain, Boots Opticians, our full-line wholesaler Alliance Healthcare Distribution Ltd and our clinical homecare specialist division, Alcura.

Boots UK operates the largest chain of community pharmacies in the United Kingdom. It is synonymous with pharmacy in the public mind and Boots is one of the country’s most trusted brands.

Our company has around 2,477 stores trading under the Boots brand, of which 2,390 have a pharmacy. These are located in all the places where people live, shop, work and travel, with many open well beyond normal office hours and at weekends. Our chain encompasses pharmacies which serve small local communities, including some of the most deprived locations in the country, and health centres through to those which are part of the largest retail and destination shopping centres.

Boots stores are readily accessible to almost everyone in the UK. Nearly 500 of them have been in the same prime high street location for more than 40 years. It is estimated that 88% of the UK’s population is within a 10 minute drive of a Boots store, and 98% within a 20 minute drive.

1. Summary

1.1 Boots UK, and the wider Alliance Boots group, operate right across, and in support of, primary, secondary and community care providing a wide range of valued public health services and wellbeing advice, supporting patients with multiple long term conditions, and providing vital medicines to care homes.

1.2 Our vision for healthcare seeks to reshape understanding of primary, secondary and community care by positioning community pharmacy as a first port of call for healthcare and public health needs. Increasing accessibility to healthcare in the first instance and ensuring a greater number of services are available in those locations is the foundation of better public health, early intervention and the prevention of disease. This will also release the capacity across primary and secondary care to deliver more complex clinical healthcare services in the community, which is in the interests of patients and taxpayers.

1.3 We believe this vision was reflected in the House of Lords Select Committee on Public Service and Demographic Change recent report which recognised the need for service redesign to ensure that NHS remains financially sustainable. Ensuring healthcare services are accessible, available and affordable empowers patients to seek professional advice, supports self care, and drives a cultural change where the patient’s needs are the most important variable.

1.4 As medicines experts pharmacists have a clear role to play in helping patients self manage long term illness and disease. The New Medicines Service and Medicines Use Reviews are helping patients to better understand how to take their medicines and avoid complications arising from poor adherence leading to fewer hospitalisations and greater patient satisfaction.

1.5. The effective management of long term conditions is also dependent on healthcare professionals working together in the interests of patients, and for healthcare leaders to recognise, and respond to, the broader professional and systemic changes that have occurred over recent years. The shift of services away from...
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Secondary to primary and community care is necessary in the pursuit of a more responsive and cost effective health service with value unlocked through greater collaboration across the professions.

2. Current Challenges

2.1 A major challenge facing health and social care is the treatment of chronic illnesses. More than 15 million people—30% of the population—in the UK have one or more long term conditions. By 2025 it is projected that more than 18 million people will have at least one long term condition.319 The Department of Health estimate that 70% of the total health and social care budget is spent on long term conditions.319

2.2. Current projections, from the Office of Budget Responsibility (OBR), estimate that without service redesign NHS and social care costs will increase dramatically as our population ages. The OBR estimates that health spending will rise from 6.8% of GDP in 2016–2017 to 9.1% of GDP in 2061–2062. At the same time social care costs will increase from 1% to over 2% in the same period.320

2.3. One major challenge is that people are living longer but are not necessarily living healthier lives. Currently co-morbidity is more likely to lead to prolonged periods of time spent in hospital and the use of multiple medicines treatment.

2.4. Increase in life expectancy hasn’t resulted in a significant extension in healthy life years of the population. Average life expectancy for a male born 2008–2010 in the UK was 78.1 years while average disease free life expectancy was 63.9 years.321

2.5. Inequality within the UK remains problematic. For males born between 2006 and 2009 life expectancy in the least deprived areas in England was 81.4 years, while disease free life expectancy was 69.4 years.322 For males born in the most deprived areas of England over the same period life expectancy was 73.3 years and disease free life expectancy 54.6 years.323

3. Responding to the Challenge

3.1 Health services will have to adapt to changing circumstances. There must be a greater emphasis on community based care that can deliver accessible, available and affordable services. Accessibility to services is essential for empowering the patient in making decisions about their own health and wellbeing. Empowerment is crucial for an effective public health service with a focus on prevention and earlier diagnosis.

3.2 At the same time a more “personalised” approach to health and social care could bring cost savings to the NHS and Local Government if services can be successfully joined-up and coordinated. To ensure the quality and standards of care continue to rise, national frameworks and standards should be introduced to allow services to be benchmarked and best practice identified and adopted.

3.3 Service redesign shouldn’t cost more. Better use of existing healthcare provision such as community pharmacy would go a long way in re-orientating how services are designed and delivered. The previous Government engaged McKinsey & Co318 to examine the key areas of NHS expenditure in terms of potential efficiency savings. McKinsey found that around a quarter of the potential savings it identified (£2.7 billion-£4.1 billion) would come from “shifting care into more cost-efficient settings”. This includes moving services from secondary into primary and community care.

3.4 Improving public health is essential in managing costs and the NHS must recognise the value of disease prevention by addressing key health determinants contributing to illness and disease. Managing long term conditions more effectively through earlier diagnosis and timely intervention is crucial. As is the case with diabetes management, interventions through regular clinical checks and patient awareness are important to avoid disease progression and further complications.

Alliance Boots working in partnership in the interests of patients with cancer

Since December 2012 Alcura (formerly Central Homecare), supported by Boots UK and Alliance Healthcare (Distribution) Ltd, assumed responsibility for providing some of The Christie hospital’s pharmacy dispensing services. The Boots branded pharmacy is the first hospital pharmacy of its kind to offer both outpatient and inpatient oncology dispensing services. In addition many patients who need medication after an outpatient consultation will be able to have it delivered to their home or collect their medication from a local Boots UK pharmacy. This partnership is already delivering benefits to patients and enables the Christie Pharmacy team to concentrate on delivering enhanced clinical pharmacy services to patients.

319 Kings Fund and Centre for mental Health “Long-term conditions and mental health: The cost of co-morbidities” (2012)
319 Department of Health “Improving the health and well-being of people with long term Conditions” (2010)
320 Office for Budget Responsibility “Fiscal Sustainability Report” (2012)
Furthermore those affected by cancer will benefit from the advice and support of Boots Macmillan Information Pharmacists. Boots UK and Macmillan Cancer Support launched the new service in September, training over 500 pharmacists to enable them to talk to the millions of people affected by cancer about the wider, practical and emotional issues they may experience.

4. The Role for Community Pharmacy

4.1 These steps will not require significant new investment or services but the better use of what already exists. The 11,406 community pharmacies in England are well placed to deliver public health services and care to patients with long-term conditions. Pharmacists are highly qualified healthcare professionals, trained in medicines management and advising on health issues.

4.2 Pharmacies currently provide a range of services including, but not limited to, smoking cessation, NHS health checks, medicines use reviews, alcohol and drug user services, sexual health screening and treatment, weight management services, vaccinations, minor ailment schemes and medicines management and adherence support.

4.3 Nearly 99% of the population can access a community pharmacy within 20 minutes. They operate where people live, work and shop and are a mainstay on high streets across the country including in deprived areas or rural communities where accessibility to other primary care services are often limited. For the estimated 500,000 people in the UK, who are not registered with a GP, community pharmacy provides vital access to health services and advice.

4.4. As highlighted in the case studies below, Community Pharmacy provides healthcare that is accessible and convenient. Many operate extended opening hours including weekends when other primary care services are often not available. The convenient and universal access to highly trained pharmacists providing ready advice and help alleviates the need to visit a GP in the first instance and provides the major point of access to healthcare to those not registered with a doctor.

4.5. The projected increase in the number of people suffering from long term conditions will continue to have huge implications for health spending and the NHS must focus on removing duplication and inefficiency in the system. Community pharmacy already contributes strongly to the efficiency of the NHS. The National Audit Office found that between 2005 and 2009 pharmacies became 8% more efficient (delivering 17% more volume for only an 8% real-terms increase in funding). In addition, purchasing efficiencies driven by pharmacies had saved the NHS over £1.8 billion. These savings continue to be made, with prescription volumes having risen 70% in the past decade.

Delivering anticoagulation clinics for patients

Boots UK manages the Community Pharmacy Anticoagulation Management Service (CPAMS) for NHS Brighton and Hove, for patients prescribed Warfarin (approximately 1.5% of the UK population). This has delivered benefits for patients and for the local NHS.

— Improved access for patients - appointments available at 17 different pharmacies geographically spread across NHS Brighton and Hove, with clinic availability on weekdays, early mornings, late nights and also on a Saturday. Clinic capacity is regularly reviewed to ensure that sufficient appointments are available where patients want them with two new clinics recently opened in Hove due to high demand in this locality. Follow up appointments are booked at the time of the previous appointment and are tailored to the condition of the patient and previous results.

— Introduced point of care finger prick testing, instead of venous sampling. This is less painful for patients.

— Provides instant access to test results giving patients an opportunity to discuss results and any dosage changes with the pharmacist on a one to one basis at the time of testing. Also patients usually see the same pharmacist, which has built great relationships, trust and confidence in the service. Reduces traveling and waiting times for patients through individual appointment times.

— Achieved overall patient satisfaction of 98% as measured by a survey in 2011.

— Delivered clinical outcomes, which are exceeding national targets. Patient time within target INR range is 79% compared to national target of 70%. Number of patients within INR range at point of test is 67% compared to national target of 60%.

— Reduced numbers of patients not attending appointments and introduced a robust follow up process for patients who do not attend an appointment to ensure they are contacted straight away. Number of patients not attending is 3% throughout the service, which is below national targets.

— Established a domiciliary service for those patients assessed as housebound, who are also provided with instant access to results and pharmacist consultation.

324 Department of Health “Pharmacy in England: building on strengths, delivering in the future” (2008)
325 NAO “The community pharmacy contractual framework” (March 2010)
NHS Health Checks

The NHS is not meeting its targets for offering NHS Health Checks to people aged 40–74 years, with only 1.4 million of the required 2.4 million-a-year offers being made at the end of 2010. Many people in full-time employment would find longer opening hours and high street locations of community pharmacies more convenient. Boots UK estimates that it could deliver up to 100,000 Health Checks a year, helping to meet the NHS target for achieving long-term savings through early diagnosis of health issues. This equates to saving the NHS £2.5 billion over the next 20 years.

5. SUPPORTING PATIENTS THROUGH MEDICINES ADHERENCE

5.1 Boots pharmacists in England and Wales carried out over 760,000 Medicine Check-ups during 2011–12 and played an important role in the launch of the NHS “New Medicine Service” in England.

5.2 The New Medicine Service (NMS) was introduced in 2011 and provides support for people newly prescribed a medicine to help improve medicines adherence. The service has initially focused on particular patient groups and conditions, including Asthma, COPD, hypertension and Type 2 diabetes. It is improving patient adherence and increases the patient’s engagement with their condition and medicines, supporting patients in making decisions about their treatment and self-management.

6. SUPPORTING PATIENTS WITH DIABETES

6.1 Boots pharmacy services are characterised by a condition led approach: Diabetic patients are offered a wide range of services, tailored to the individual. We offer day to day access to expert advice around all aspects of diabetes management, helping people to understand their medication, offering support for self-care and signposting local support organisations.

Boots UK and Diabetes UK Diabetes Risk Assessment service—empowering

Supporting diabetic patients through the New Medicines Service (NMS)—feedback from Boots pharmacists

“Mr W signed up to the New Medicines Service in 2012, having been recently diagnosed with diabetes. I initially spoke to him on the phone. He has had gliclazide added to his metformin and I asked how he was getting on with the medication. He has had no problems and is due to have a review in about two weeks when the dose may need to be stepped up. When I asked what support he had received since he was diagnosed with diabetes he told me he had been told to eat things that he didn’t like. I explained to Mr W that we have an information pack at Boots that gives guidance of what care is important to his health. I explained about the importance of an annual eye test and foot care. Mr W says that his vision has altered recently and the sensation in his feet is also different. I discuss why this is of concern for diabetics. He says he will call into the store. That afternoon Mr W came in to collect an information pack on his way to the opticians!

“NMS sign up for a young mum using metformin for recently diagnosed diabetes—news of her condition had left her bewildered and anxious. We discussed lifestyle changes advice, diet and the best way to manage condition as she had also been diagnosed with high blood pressure. I gave her a leaflet on Diabetes booklet and on blood pressure. Further guidance was given as she had a young baby to look after as well. We developed a management plan that would fit around her family and reassured her that she could always come to the pharmacy. This has made a tremendous difference and put a smile on her face again.”

6.2 Looking after eye health and regular eye checks are really important for diabetic patients and ongoing support is offered by Boots Opticians. A large volume of undetected (and untreated) eye conditions are picked up during routine sight tests. Optometrists play an important role in the detection of glaucoma, cataract, age-related macular degeneration, diabetes and diabetic retinopathy.

6.3 Once patients have been established on treatment for diabetes, then there is a continuing need for support to ensure that they get the best from their medication. This is particularly important when the effects of the disease, or related complications such as high blood pressure, may not be immediately obvious. Pharmacies should also be able to support patients on a continuous basis, as necessary, with advice, aids or devices, and/or reminders (such as charts or text messages). Increased medication adherence should help maintain health and prevent or delay the development of complications, reducing hospital admissions.

326 NAO “The management of adult diabetes services in the NHS” (May 2012)
6.4 With the number of people with diabetes set to increase to 3.8 million by 2020,\textsuperscript{327} demand for screening, monitoring and treatment for diabetes is set to rise considerably. The NHS must make the most of existing primary care services, skills and expertise to meet this challenge.

\textit{9 May 2013}

\textbf{Written evidence from Novo Nordisk (LTC 54)}

\textbf{SUMMARY}

\begin{itemize}
\item The prevalence of diabetes is rising in parallel to rising rates of obesity putting increasing pressure on NHS services and driving up costs.
\item Without appropriate management and support, people with diabetes are at significant risk of developing a range of complications including cardiovascular conditions.
\item Novo Nordisk welcomes action being taken by the Government to prioritise diabetes, including the expected publication of \textit{Action for Diabetes}; however, this must be backed up by clear implementation plans.
\item Efforts to reduce obesity and thereby reduce diabetes rates must be clarified and Public Health England should outline its plans to tackle rising levels of obesity.
\item Integrated care will be key to delivering improvements for all long-term conditions, including diabetes. Health and wellbeing boards are in a strong place to develop this agenda, joining-up health and social care services.
\item Health and social services and local authorities must be prepared to meet the challenge of an ageing population and the attendant long-term conditions and co-morbidities. The scale of the challenge is illustrated clearly by the "Barnet graph of doom".
\item There is a lack of information and clarity around the burden of long-term conditions such as diabetes in social care settings. In order to deliver effective, integrated health services to social care users, more must be done to identify people with long-term conditions—and co-morbidities—and to ensure that they receive the treatment and care they need without needing to be admitted to hospital as an emergency. Action in this field will be vital in improving care for people with long-term conditions such as diabetes and to make services sustainable.
\item Novo Nordisk is undertaking work to estimate the number of people with diabetes in social care settings and the cost of their care, and indeed the mismanagement of their condition, to health and social care budgets.
\item In addition, Novo Nordisk is working with the King’s Health Partnership to co-create a world-recognised centre for diabetes care, research and education. We hope to demonstrate the benefits of integrated, joined-up working to patients and to the NHS.
\end{itemize}

1. \textbf{INTRODUCTION AND BACKGROUND}

1.1 Novo Nordisk strongly welcomes the focus on diabetes being taken by the Health Committee. Diabetes is rapidly becoming one of the most pressing public health issues with three million people now diagnosed with diabetes and 850,000 people unaware they have the condition.\textsuperscript{328, 329} In the next 20 years, the number of people diagnosed with diabetes is expected to rise to 5.6 million at a cost of £39.8 billion to the NHS and to the wider economy.\textsuperscript{330}

1.2 Diabetes significantly increases the risk of developing a number of potentially life-threatening complications including stroke, cardiac failure and renal failure, as well as blindness and major limb amputations. It is estimated 80\% of the cost of diabetes is avoidable through effective and timely interventions to prevent complications.\textsuperscript{331}

2. \textbf{IMPROVING DIABETES CARE}

2.1 A clear and comprehensive strategy for tackling diabetes is urgently needed. We await the publication of Action for Diabetes, which we hope will provide that strategy. While we are encouraged by the work that is taking place to ensure diabetes remains a priority for the NHS, we believe that the implementation document must take a holistic view of care in the NHS and beyond. In particular, the implementation guide must address how to reduce the variations that exist in diabetes care and outcomes across the country.

\textsuperscript{327} NAO “The management of adult diabetes services in the NHS” (May 2012)
\textsuperscript{329} Hex N et al, Estimating the current and future costs of Type 1 and Type 2 diabetes in the UK, including direct health costs and indirect societal and productivity costs, \textit{Diabetic Medicine}, 29: 855–862, 2012
\textsuperscript{330} Hex N et al, Estimating the current and future costs of Type 1 and Type 2 diabetes in the UK, including direct health costs and indirect societal and productivity costs, \textit{Diabetic Medicine}, 29: 855–862, 2012
\textsuperscript{331} Hex N et al, Estimating the current and future costs of Type 1 and Type 2 diabetes in the UK, including direct health costs and indirect societal and productivity costs, \textit{Diabetic Medicine}, 29: 855–862, 2012
2.2 There are already levers and incentives in place to improve diabetes care, for example the Quality and Outcomes Framework (QOF) incentivises GPs to undertake a variety of care processes for people with diabetes. These must be kept under constant review in order to ensure they are fit for purpose. Furthermore, new levers should be developed and effectively implemented so that care for people with diabetes is constantly improving. These should include additional indicators on diabetes in the QOF and the clinical commissioning group outcome indicator set (CCGOIS). Furthermore, Commissioning for Quality and Innovation (CQUIN) payments should be developed and implemented to drive further improvement across the NHS.

3. Obesity And Diabetes

3.1 There is a wealth of evidence linking rising rates of diabetes to rising rates of obesity. An obese man is five times more likely to develop type 2 diabetes than an average weight man and an obese women is more than thirteen times more likely.\textsuperscript{332} In England, 25% of adults are obese, with 42% of men and 32% of women overweight.\textsuperscript{333} It is predicted that if no action is taken, 60% of men, 50% of women and 25% of children in Britain would be obese by 2050.\textsuperscript{334}

3.2 Several European countries have introduced taxes on unhealthy food and beverages, such as sugary drinks, as part of their efforts to counter obesity.\textsuperscript{335} While the impact of imposing a tax on sugary drinks is unknown, the Government must ensure manufacturers follow the voluntary measures laid down in the Responsibility Deal.

3.3 As of April 2013, obesity has become part of the Public Health Domain of the Quality and Outcomes Framework, which will be managed by Public Health England (PHE). It is essential that PHE implements preventative measures to ensure people, particularly children, are supported to moderate their sugar and fat consumption.

4. Treatment in Community Settings and Integrated Care

4.1 When people do develop diabetes, effective integrated care will be key to ensuring that they receive the care they need and are not exposed to needless risk of complications. The types of services which the average person with diabetes will need access to will depend on the specific nature of their condition, their own profile and their place in the care pathway. These can include: screening and diagnostic tests; assessments of risk factors and complications; dietary advice; lifestyle and exercise advice; education; glycaemic control and monitoring; Chronic Heart Disease risk factor control and targets; specialist referrals and specialist nursing; diabetes foot assessments and podiatry services; treatment of hypertension.

4.2 The National Institute for Health and Care Excellence (NICE) has recommended that all people with diabetes receive nine healthcare checks. Ensuring that people with diabetes receive the nine care processes recommended by NICE will require close working between healthcare professionals across the NHS. The challenge for the new system is to break down boundaries between different parts of the health and care system. There is an opportunity for health and wellbeing boards (HWBs) to lead this agenda, given the representation of both the NHS and local government on these boards. Silo-ed budgets have been a barrier to integrated care and HWBs should make a concerted effort to pool budgets across different areas of the care pathway to improve services for patients.

4.3 This should be coupled with reforms to tariffs for services for patients with long-term conditions which continue to act as an obstacle to delivering a joined-up system. The year of care tariff for long-term conditions presents a real opportunity to move away from paying providers by episode of care and instead treating patients as individuals with complex care needs by focusing more on prevention and condition management in the community. This will improve outcomes for patients and deliver much needed efficiencies in the way care is delivered.

5. Readiness of Services to address Diabetes and Multi-Morbidities

5.1 Novo Nordisk further welcomes the focus of the committee’s investigation of the readiness of social care services to treat patients with long-term conditions, such as diabetes, in the community. Every year thousands of people enter the social care system, the majority of whom are over the age of 65. The prevalence of diabetes amongst the over 65s is higher than in the general population, yet little is known about the prevalence of diabetes amongst social care users.

5.2 In 2007, the Department of Health estimated that 1 in 20 people with diabetes incur social services costs. The presence of complications increased social services costs four-fold.\textsuperscript{336}

5.3 There is widespread recognition that a rapidly ageing society means more people living with chronic long-term health conditions, such as diabetes, placing pressure on health and social care costs.\textsuperscript{337} A report by

\textsuperscript{332} Department of Health, Healthy Lives, Healthy People: A call to action on obesity in England, October 2011

\textsuperscript{333} NHS Information Centre, Statistics on Obesity, Physical Activity and Diet: England, 2012

\textsuperscript{334} Government Office for Science, Foresight, Tackling Obesities: Future Choices, October 2007


\textsuperscript{336} Dr Sue Roberts, National Clinical Director for Diabetes, Turning the Corner: Improving Diabetes Care, 2007

\textsuperscript{337} House of Lords Select Committee on Public Service and Demographic Change, Ready for Ageing?, March 2013
the House of Lords Select Committee on Public Service and Demographic Change predicted that the demand for health and social care for people with diabetes in England and Wales will increase by 45% from 2010 to 2030.338

5.4 Social care services must work closely with health services to ensure that social care users receive the treatment and support they need to maintain good blood glucose and to prevent complications which will result in hospital admissions. This will become increasing acute as the older population, and consequently demand placed on adult social care and health services, rises.

5.5 The scale of the challenge to social care services of an ageing population has been clearly demonstrated by the Barnet “Graph of Doom”.339 It is essential that local authorities and local health economies are equipped and prepared to meet this challenge.

5.6 Meaningful data on the prevalence and management of long-term conditions, such as diabetes, in social care settings are needed. As mentioned above there is little comprehensive evidence available on the treatment of long-term conditions in social care. Novo Nordisk is undertaking work to uncover the significant contribution of diabetes to local authority social care costs.

6. MENTAL HEALTH AND DIABETES

6.1 The complications related to diabetes are not just physical. Novo Nordisk’s Diabetes Attitudes, Wishes and Needs (DAWN2) project asked people with diabetes about their experiences of having the condition. Across all people with diabetes, sleeping problems and depression were the most commonly reported.340 It is estimated that people with diabetes are two to three times more likely to have depression than the rest of the population.341

6.2 It is essential that the mental health of people with long-term conditions, such as diabetes, is considered alongside and equal to their physical wellbeing. Failure to support people with diabetes is associated with poorer glycaemic control, more diabetic complications and poorer medicines adherence.342

7. EXAMPLES OF WORK TO IMPROVE SERVICES

7.1 As part of the DAWN2 project, Novo Nordisk aims to provide enhanced support and education for people with diabetes in order to improve understanding amongst people with diabetes of the need for good glucose management and to give them the help they need to manage their condition effectively.

7.2 In addition to the project on social care, Novo Nordisk is currently engaged in a significant project with King’s Health Partners, comprising Guy’s and St Thomas’ Hospital and King’s College Hospital London, to demonstrate how the NHS and the pharmaceutical industry working in partnership can develop a model for sustainable diabetes care, research and education. The ambition of this joint working project is to co-create a world-recognised centre for diabetes care, research and education: developing and delivering the most cost-effective, highest quality care, ensuring optimal outcomes to patients served by King’s Health Partners.

The expected outcomes and benefits to patients and the NHS of the joint working project are as follows:

— The development, design and delivery of integrated diabetes care, across the King’s Health Partnership area for optimal cost-effectiveness and outcomes.
— Identification and development of infrastructure to support an integrated model.
— Clear and costed, evidence-based, quality-controlled pathways for all diabetes patients, with medicines used appropriately to deliver optimal outcomes.
— Creating the infrastructure for ongoing innovation and collaboration in research and clinical trials.
— Developing opportunities to expand the current research portfolio.
— Development of a cost-effective solution to diabetes care retaining patient access to high quality diabetes care and treatments.
— Identification of high-impact interventions to benefit people with diabetes.

8. ABOUT NOVO NORDIK

8.1 Novo Nordisk is a global healthcare company with 90 years of innovation and leadership in diabetes care. The company also has leading positions within haemophilia care, growth hormone therapy and hormone 

338 House of Lords Select Committee on Public Service and Demographic Change, Ready for Ageing?, March 2013
340 Novo Nordisk, Diabetes Attitudes Wishes & Needs, November 2012
replacement therapy. Headquartered in Denmark, Novo Nordisk employs about 32,500 people in 74 countries and markets its products in 179 countries.

9 May 2013

Written evidence from the National Housing Federation (LTC 55)

1. The Scope for Varying the Current Mix of Service Responsibilities so that more People are Treated Outside Hospital and the Consequences of such Service Re-Design for Costs and Effectiveness

1.1 There is real potential to alter the current mix of service responsibilities to ensure people are able to live and receive treatment in their own home, rather than in hospital. Good housing is a fundamental part of this kind of care and support, as it helps people to manage their conditions more effectively and independently.

1.2 Housing is a vital part of an integrated health and social care system, which prioritises preventative care and speeds a person’s recovery to independence. The White Paper “Caring for our Futures” supports this, stating: “housing plays a critical role in supporting people to live independently, and helping carers to support others more effectively ... Fragmented health, housing, care and support are letting people down. A failure to join up also means that taxpayers’ money is not used as effectively as possible, and can lead to increased costs for the NHS.”

1.3 Joining-up health, care and housing would produce clear benefits in terms of both costs and improved outcomes for those living with long-term conditions. Department of Health research\(^343\) has found that investment in housing-based care services (rather than more traditional services like residential care) produces better health outcomes and gives people greater independence. It also reduces costs for the taxpayer by avoiding hospital admissions and reducing the number of children taken into care. Our report, “Providing an Alternative Pathway”, shows how housing can be used effectively as a health and care service and highlights the savings that can be made. It showed that integrated services can deliver savings of up to £17,992 per person per year, when compared to less integrated pathways. In one of the report’s examples, a housing service saved a total of £241,670 to local health and social care budgets in just 18 months.

1.4 More specifically, investment in housing-related support services are also cost-effective as they often reduce the need for more intensive care interventions, such as a move to a care home.\(^344\) A review of the Supporting People programme (which funded housing related support services from 2003–09)\(^345\) found that a £1.6 billion investment in housing-related support services generated an annual cost saving of £3.41 billion to the taxpayer.

1.5 Frontier Economics found that capital investment in specialist housing with care and support for nine client groups delivered an annual net benefit to the exchequer of £639 million. This includes £219 million a year from older people’s housing, £199 million a year from specialist housing for adults with learning disabilities and £187 million a year from specialist housing for people with mental health problems.\(^346\) The Department of Health has since highlighted the findings of this research to local authorities commissioning these kinds of services\(^347\).

2. The Readiness of Local NHS and Social Care Services to Treat Patients with Long-Term Conditions (Including Multiple Conditions) within the Community

2.1 Although there are examples of innovative services which allow those with a long-term condition to be managed within the community, they are not yet common practice. Partnerships between the local NHS, social care commissioners and housing providers are key to achieving better outcomes and reducing costs, yet a number of significant barriers to full integration still remain across the design, commissioning and delivery of services. One of the main challenges is the need to join-up strategic and local commissioning between housing, social care and health.

2.2 NHS trusts and local commissioners need to focus on preventing hospital admissions and readmissions by investing in support services and specialist housing. Housing organisations have a good track record of providing specialist housing and delivering services focussed on restoring independence—for example, by adapting the homes of people with long-term conditions to prevent falls and other accidents. These services have been proven to prevent admission and readmission to hospital, allow re-ablement after an accident or illness, delay the need for intensive care services and reduce the likelihood of emergency admissions.\(^348\) One

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\(^343\) Department of Health (2009), Support Related Housing Incorporating Support Related Housing into your Efficiency Programme

\(^344\) National Housing Federation (2013), Providing an Alternative Pathway

\(^345\) Cap Gemini (2009), Research into the financial benefits of the Supporting People programme

\(^346\) Homes and Communities Agency (2010) Frontier Economics—Financial Benefits of Investing in Specialist Housing for Vulnerable and Older People

\(^347\) Department of Health (2010): LASSL (DH) page 19

\(^348\) National Housing Federation (2011), On the Pulse
case study of an individual with dementia living in Extra Care housing shows savings of up to £17,222 a year to health and social care budgets.\textsuperscript{349}

2.3 The Federation’s most recent report, “Dementia: Our Housing Challenge”, highlights how the NHS and social care commissioners can use housing as part of the treatment for people living with dementia. Dementia is a significant challenge for the NHS with an estimated 40% of hospital beds occupied by people with dementia.\textsuperscript{350} Currently 60% of people with dementia enter hospital from their own home, but just 36% return home after discharge.\textsuperscript{351} People with dementia stay longer in hospital than other patients who go in for the same procedure and are often subject to delays when leaving.\textsuperscript{352} The longer the hospital stay, the worse the effect on the symptoms of dementia and the person’s physical health. Longer admissions also make discharge to a care home and the prescribing of antipsychotic drugs more likely,\textsuperscript{353} which are often not the best option for the patient. People with dementia in hospitals are also dying at a significantly higher rate than people without the condition.\textsuperscript{354}

2.4 The Dementia Commissioning for Quality and Innovation (CQUIN) payment framework aims to incentivise the identification of patients with dementia to ensure appropriate referral and follow up after they leave hospital. Part of this referral stage should include engagement with services in the housing sector to ensure patients are able to return home as quickly as possible.\textsuperscript{355} There is a need for similar incentives for early-intervention across the health and care system to ensure people get the support they need to live independently for as long as possible.

3. The Practical Assistance Offered to Commissioners To Support the Design of Services Which Promote Community-Based Care and Provide for the Integration of Health and Social Care in the Management of Long-Term Conditions.

3.1 For effective integration, it is crucial that housing be considered at every stage of service planning, commissioning and delivery. However, there is a lack of practical assistance for commissioners to support them in redesigning services to support independent living in the community and to support integration of services across housing, health and social care to manage long-term conditions.

3.2 The Health and Social Care Act 2012 does not provide a specific framework for housing to engage with health and vice versa. Though the draft Care and Support Bill creates an environment more conducive to this, it does not guarantee it. We are particularly supportive of Clause 4 in the draft Bill, which promotes co-operation between the local housing authority and the adult social services departments. These two teams should work together to identify gaps in specialist housing provision by establishing and maintaining a register of adapted and accessible housing, as part of their oversight of the local care market.

3.3 However, the draft Bill is lacking a duty for co-operation between health and housing. Local authorities, the NHS and other local partners must align priorities and funding streams to both deliver and gain local support for services like specialist housing. The Bill and accompanying guidance could do more to ensure local authorities consider housing when recommending the most relevant service for a patient’s circumstances. This would also encourage Clinical Commissioning Groups and Health and Wellbeing Boards to see specialist housing and related adaptation and support services as part of the solution when considering an individual’s care and support needs.

3.4 The draft Bill needs to be amended to support local authorities to join up housing, care and health to create more outcomes-focused commissioning through pooled funding. This will provide vital preventative care and support services, saving the NHS and local authorities a significant amount of money by reducing demand and providing effective alternatives through more preventative services that intervene earlier or cost less than traditional service.

4. The Ability of NHS and Social Care Providers to Treat Multi-Morbidities and the Patient as a Person Rather than Focusing on Individual Conditions

4.1 The most effective examples of the NHS and social care providers treating multi-morbidities arise when the patient is treated as a person, rather than just for one individual condition or illness. While there are many NHS and care services that do this already, it is far from the standard experience of health and care. To achieve this more consistently, local authorities and the NHS need to engage and partner with services traditionally viewed as “health-related” like housing. Housing associations are more than just an important stakeholder in local service provision. Experienced community providers like housing associations can be the driver and delivery channel for integrated offers that respond to the whole person. This might include a specialist package of support and accommodation, or simply a co-ordinated offer of a timely home adaptation.

\textsuperscript{349} National Housing Federation (2013), Providing an Alternative Pathway
\textsuperscript{350} Department of Health (2010), Quality outcomes for people with dementia: building on the work of the National Dementia Strategy
\textsuperscript{351} Alzheimer’s Society (2009), Counting the Cost: Caring for People with Dementia on Hospital Wards
\textsuperscript{352} Department of Health (2012), Using the Commissioning for Quality and Innovation (CQUIN) payment framework Guidance on new national goals for 2012–13
\textsuperscript{353} Alzheimer’s Society (2009), Counting the Cost: Caring for People with Dementia on Hospital Wards
\textsuperscript{354} Care Quality Commission (2013), Care Update
\textsuperscript{355} Care and Repair England (2012), Home from Hospital Pack
4.2 For example, housing can play a key role in end-of-life care, when patients often have several different illnesses. The Good Death project, established by Public Health North East and managed by the housing association Home Group, brought together housing, health and social care services to make practical arrangements for residents to enable them to remain in their own homes for as long as possible at the end of life. A support officer worked with 63 people over the course of nine months to make small adjustments to their living conditions. The project saw a 10% reduction in accident and emergency attendances, and a 55% cut in GP consultations among its clients. Participants also reported a 65% increase in their feeling of “being in control” over the course of the project, and a 74% increase in their quality of life.

4.3 However, in a recent survey by the Local Government Information Unit, only a quarter of councils said that their housing departments were engaged with end-of-life care issues, despite the often crucial role of housing in improving the quality of a person’s life when they have multiple morbidities near the end of their life. The survey also found that many councils see end-of-life care as being a priority, but have yet to put in place the necessary structures to deal with it.

4.4 As the new commissioning structure beds in, health providers and commissioners should be open to developing new partnerships that meet the needs of the whole person. This could include partnering with housing providers to create clearer referral routes between services, and using the home as a hub to deliver care. Clinical Commissioning Groups should also be open to these kinds of approaches when deciding how to commission, as well as what services to prioritise. Health and Wellbeing Boards can also play a role by supporting the pooling of funds or appointing a lead commissioner to deliver more integrated services in the local area.

5. **Current Examples of Effective Integration of Services Across Health, Social Care and Other Services which Treat and Manage Long-Term Conditions**

5.1 For integration to be effective, Health and Wellbeing Boards and Clinical Commissioning Groups need to look beyond traditional health and care interventions. When services like housing-related support can be accessed as part of a wider package of support, individuals are able to both manage multiple and long-term conditions more effectively, and pressure on the NHS alleviated.

5.2 The following examples show how housing can be effectively integrated across health and social care:

- **Housing with care and support** enables people to remain independent and receive care services in their own home rather than moving to a care home.

- **Preventative services**, such as housing-related support, reduce the need for more intensive care, reducing overall demand on the care system by helping people live independently in their own home.

- **Reablement services** get people home from hospital quickly, prevent hospital readmissions and help them to recover their independence after illness.

- **Timely home adaptations** assist with discharge home from hospital, facilitate the delivery of care in people’s own homes, and encourage independent living.

- **Good quality homes** help to maintain good health, speed recovery from illness and reduce the incidence of respiratory and other diseases.

5.3 If housing is effectively used to help treat long-term conditions, demand on the care system would be reduced and the reach and outcomes of existing care services would be improved. Appendix 1 details further examples of well integrated services which effectively treat and manage long-term conditions.

6. **The Implications of an Ageing Population for the Prevalence and Type of Long Term Conditions, together with Evidence about the Extent to which Existing Services will have the Capacity to Meet Future Demand.**

6.1 The likelihood of disability, illness and poor health increases as people age. More people are living longer with more complex conditions such as dementia and chronic illness. An estimated 3.9 million (33% of people aged 65–74 and 46% of those aged 75+) have a limiting long-standing illness and there are 700,000 people in the UK with dementia, with numbers likely to increase to 1.4m in the next 30 years.

6.2 Levels of unmet need in terms of care and support for older people are deeply worrying. Budget increases for social care have failed to keep pace with the needs driven by demographic change and rising costs of equipment and staff. Many thousands of vulnerable people are still not receiving the care or support they need. The Commission for Social Care Inspection estimated a shortfall of 1.4m hours of care in 2006–07 to 450,000 older people.

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356 North East Health Innovation and Education Cluster
357 LGiU (2013), *A Good Death: The Role of the Local Authority in End of Life Care*
358 Department of Health (2009), *Living well with dementia: a national dementia strategy*
359 All Party Parliamentary Local Government Group (2008), *Never Too late for living: Inquiry into services for older people*
6.3 Some specialist homes are being developed for older people, but as demand outstrips supply older people will find it increasingly difficult to secure a suitable property. Supply in some areas is falling rather than rising, as traditional forms of sheltered housing are decommissioned where they no longer meet current expectations. A conservative estimate suggests there are already around 70,000 people aged 60+ in urgent need of housing and related support services. However, an ageing population brings new opportunities to develop housing and services which take into account the high levels of owner occupation and housing equity owned by older people. Households of people over 65 collectively own around £500bn of unmortgaged property equity, while over 50s account for 40% of consumer spending, 60% of UK total savings, and 80% of the nation’s wealth.

7. THE EXTENT TO WHICH PATIENTS ARE BEING OFFERED PERSONALISED SERVICES

7.1 In its 2010 Adult Social Care Strategy, the UK government set an ambitious target of having all council-funded service users and carers on personal budgets, preferably as a direct payment, by April 2013. As of March 2012, 53% of on-going users of community services in England were on personal budgets, an increase of 38% on the March 2011 figure.

7.2 The Federation, however, is concerned that an emphasis on personal budgets overshadows the full benefits of personalisation. The principle of personalisation encourages concentration on outcomes determined by people and communities and engaging solutions beyond the narrow definitions of social care. The overall aim is to secure a shift to a position where as many people as possible are enabled to stay healthy and actively involved in their communities for longer and delaying or avoiding the need for targeted services.

7.3 To achieve this aim, local authorities need to facilitate a broad range of choice in the local care and support market, including housing options, and personalise the way in which care and support services are delivered wherever people live. Local councils, the NHS and their local partners need to integrate health and social care commissioning around agreed outcomes to support independence, working closely with housing providers to continue developing a wide range of options that enable independent living.

7.4 This will help to promote the delivery of a broader range of housing, home adaptations and support service designed to offer living environments which enable people with care and support needs to live independently in the community. Once an effective care market is in place, people also need to have the information and advice, including advice on housing options and adaptations, to make care and support decisions which work for them.

APPENDIX 1

CASE STUDY 1: HOUSING AND INDEPENDENT LIVING

Andy, aged 32, was diagnosed with schizoaffective disorder and Bi-Polar affective disorder when he was 18 and has a long history of acute in-patient admissions and safeguarding concerns. A rehabilitation service, provided by the housing association Look Ahead, has helped him to live independently in a relatively short period of time and at less cost than residential care—the more common approach. It is estimated that this service has saved the NHS and local authority £241,670 by enabling Andy’s quick transition from in-patient service to living with only minimal need for care and support.

Look Ahead’s service provides intensive support for up to 11 individuals in self-contained accommodation and is staffed 24 hours a day. Residents have usually come from residential care and long-term in-patient stays prior to moving in and the service supports them to become fully independent. The service is a product of integrated working at its best as it was originally commissioned as part of a joint commissioning strategy by the local NHS and local authority following the closure of an in-patient rehabilitation ward.

One year after moving to the rehabilitation service, Andy successfully applied to do a nursing diploma at City University, and volunteers for Tower Hamlets Centre for Mental Health. Six months later, Andy moved to his own flat with continued support from Look Ahead’s floating mental health service. Once Look Ahead is happy that he is well settled and can live independently, he will be discharged from the service.

CASE STUDY 2: LIVING IN THE COMMUNITY

Anna, aged 30, has autistic spectrum disorder and a learning disability. She does not use words to communicate. After a year in an assessment and treatment hospital, Anna is now happily living in her own home, developed by Dolphin Square Foundation and managed by Yarrow in London, with round the clock support from a small well-trained team.

361 HGO Consultancy for the National Housing Federation (2010)
362 All Party Parliamentary Local Government Group (2008), Never too late for living: Inquiry into services for older people
363 Communities and Local Government Department (2008), Lifetime homes, lifetime neighbourhoods: a national strategy for housing in an ageing society.
364 Department of Health (2010), A Vision for Social Care
365 Association of Directors of Adult Social Services (2012), Annual Survey of Councils
366 National Housing Federation (2013), Providing an Alternative Pathway
Close partnership working between three main agencies—Westminster Social Services, Kingswood NHS Assessment and Treatment Unit and Yarrow—meant that there was a shared awareness of Anna’s very complex needs and a joint willingness to seek solutions. Throughout the planning process, Yarrow Housing and the Dolphin Square Foundation frequently met with Westminster social services and Kingswood NHS Assessment and Treatment Unit to identify ways of improving the living environment for Anna. Triple glazing and sound proofed walls ensure that neighbours are not disturbed by Anna’s vocalisations or loud music. A chromotherapy bath, which provides a body massage with a whirlpool with coloured jets, was fitted to help Anna relax, be calm and have fun.

If Anna had not moved to her new home, she is highly likely to have remained in an assessment and treatment service, which would not have benefited her overall wellbeing. Not only are the fees for this type of service £3,500 per week, but the review of Winterbourne View highlighted the importance of reducing long-term stays in assessment and treatment centres. After the initial service to support Anna’s transition to her new home tapers off, this services shows an annual saving to health and social care budgets of £17,992, as compared with Winterborne View.

**CASE STUDY 3: IMPORTANCE OF HOUSING IN WELL-BEING**

Following a motorbike accident, Bruce needed multiple operations—including the amputation of a leg—and was left tetraplegic. After his discharge from hospital, he was unable to walk or take care of himself and after three months, he attempted suicide. Bruce was referred to Papworth Trust by the senior rehabilitation consultant at Addenbrooke’s Hospital. Through the support of the housing association Papworth Trust, he is now living independently and is recovering from his severe depression in his own purpose designed home.

The specialist design of Bruce’s flat has been fundamental in enabling Bruce to live independently. The kitchen work surfaces and oven are at a height that he can use and the flat’s sinks and hob are height adjustable. Light switches are at elbow height, heating controls are accessible to him and doorways are wider than normal to allow access for his wheelchair.

**CASE STUDY 4: LIVING INDEPENDENTLY IN EXTRA CARE HOUSING**

Grace, aged 74, has dementia and until recently was neglecting her health and having difficulty managing at home on her own. Moving to an Accord Housing extra care scheme has meant that she can continue to have a home of her own, with access to care and support when she needs it.

A local authority social worker reviewed Grace’s care needs and she was referred to Accord Group’s Moxley Court extra care scheme by a joint housing and social care allocation panel. If she had been moved to a residential care home under an “Elderly Mentally Ill” placement, would have cost up to £600 per week—whereas residence in a scheme like Moxley Court only costs £300 per week.

Even with her dementia, Grace can live independently in her own self-contained flat with care and support staff available at all times. She also has access to a range of communal facilities, including a hairdressing salon and assisted bathing service. Grace says that she is much happier at Moxley Court and staff have helped her to mix with other residents in the scheme.

Living in an extra care scheme means that Grace’s care providers are able to be responsive rather than reactive. Ensuring Grace is in the most appropriate housing, with the care and support she needs, has prevented hospital admissions which may have occurred if she was left in her own flat.

**Written evidence from Epilepsy Action (LTC 57)**

This submission is from Epilepsy Action, the UK’s leading charity for people with epilepsy. Epilepsy Action would welcome the opportunity to give evidence in person to the Committee.

**SUMMARY**

— Epilepsy Action does not believe that current services are adequate to meet the health and social care needs of people with epilepsy.

— From our work on the ground, the data we collect and the experiences relayed to us by our membership, we believe the key issues on the management of long-term conditions are: inequitable access to specialists, lack of availability of specialists, and inadequate implementation of mechanisms for review/self-management (annual reviews, care plans).

— Many of the issues that prevent more successful ongoing management (and self-management) of long-term conditions could be addressed by better integration of care pathways, and instigating concerted programmes of self-management and information. The current system permits too many missed opportunities for interventions.

367 National Housing Federation (2013), *Providing an Alternative Pathway*
— A lack of funding in prevention is a barrier to meaningful progress in the area. Social care and support is too often limited to critical needs only, with too few resources allocated to developing care plans, transitional care services (a key time for developing positive health behaviours) and patient training programmes to equip and empower people to better self-manage their long term condition.

**BACKGROUND**

1. There are 496,000 people with epilepsy in England.

2. There are over 40 different types of epilepsy, and at least 40 different types of seizure.

3. More than one in five people with epilepsy have learning or intellectual disability. 368 15% with mild learning disabilities, and 30% with severe learning disabilities, have epilepsy. 369

4. There is an assumed misdiagnosis rate in the UK of between 20–31 percent. 370

5. There is a treatment gap of around 18% (52% of people with epilepsy are seizure-free compared to 70% who could be.). 371

6. Around 1,150 people a year die from epilepsy in the UK with 40% of all deaths and 59% of childhood deaths potentially avoidable.

**CURRENT SERVICES: A CRITICAL TIME FOR EPILEPSY IN ENGLAND**


8. Of acute trusts that provide an epilepsy service, only 66% (52/79) offer patients access to an adult epilepsy specialist clinician. All adults with epilepsy requiring access to a specialist, a Key Recommendation of the NICE Clinical Guidelines for the epilepsies and NICE Quality Standards.

9. Only half (52%, 475/905) of people with epilepsy told us that they have seen an epilepsy specialist nurse (ESN). Access to an ESN is a Key Recommendation of the NICE Clinical Guidelines for the epilepsies and NICE Quality Standards.

10. Nearly three quarters (73%, 495/682) of patients (adults and children) who still have seizures have never been referred to a specialist tertiary epilepsy centre.

**THE READINESS OF LOCAL NHS AND SOCIAL CARE SERVICES**

11. The statistics are from April to September 2012, included in ACT.

12. Two thirds (66%, 104/158) of prospective CCGs did not have, or intend to produce, a written needs assessment of the health and social care needs for people with epilepsy.

13. Only 17% (27/158) of CCGs or CCG confederations had appointed a clinical lead for epilepsy.

14. Of specific services considered best practice that CCGs should be considering for their local populations:
   — Only 46% intended to commission a diagnostic pathway.
   — Only 32% intended to commission a care planning service for people with epilepsy.
   — Only 9% intended to commission a GP with a specialist interest led service.

15. This illustrates the unpreparedness of many local commissioning bodies to provide services for epilepsy; even the basics as set out in the NICE Clinical Guidelines for the epilepsies and the NICE Quality Standards for epilepsy.

16. Epilepsy can be well managed in the community when good seizure control has been achieved. An example of good care delivery at or close to home is the Calderdale PCT model, where positive results have been achieved from employing a prescribing clinical pharmacist practitioner with a specialist interest in epilepsy to conduct annual epilepsy reviews and optimise treatment. 373

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17. We have concerns that specialist expertise developed in community teams could be lost as nurses are reorganised and teams incentivised to prevent admissions across the whole range of long term conditions rather than just their speciality. We believe attempts to move towards this model should be resisted.

18. Around 2,400 babies are born to women with epilepsy each year\(^{374}\) and pre-conception counselling for women of child-bearing age is an indicator in the 2013/14 Quality and Outcomes Framework.

19. Epilepsy Action’s “Ideal World for Women” 2012 survey\(^{375}\) found that over a quarter (26%, 53/204) who have been pregnant in the last five years or are planning on becoming pregnant, said a health professional had not discussed epilepsy and pregnancy with them. From “ACT”, over a third (36%, 131/366) of women with epilepsy of child bearing age have never received information and counselling on contraception, conception and pregnancy.\(^{376}\)

20. All pregnancies in women with epilepsy are classed as high risk. Women with epilepsy and their unborn babies potentially face an increased risk of problems during pregnancy and birth.

21. Even where epilepsy services can be safely and effectively provided by local generalists, incentivised by payment tariffs, they are not available to all patients. We believe this is in part because of the low profile for neurological conditions. We hope the introduction of clinical senates and a Strategic Clinical Network for Mental health, dementia and neurological conditions will go some to addressing this.

22. Access to quality, straightforward advice and information is crucial to enable patients with long-term conditions to be independent. Information creates informed patients, and informed patients experience better outcomes.

23. Of our patients surveyed last year (ACT), less than half (44%, 412/947) of patients reported that they had been provided with general epilepsy information from a health professional.

24. Only half (50%, 472/947) of patients reported being given information about their medication and its effects from a health professional.

25. Information provision is one easily addressable area where the NHS, local authorities and Department of Health is not meeting expectations, and one where better signposting and greater care and attention could achieve an instant impact.

26. Only 27% (27/102) of local authorities Joint Strategic Needs Assessments included a section that mentions the care of people with epilepsy.

27. This demonstrates that medium to low prevalence medical conditions like epilepsy are unlikely to be addressed in the immediate future by the new health and public health structures. These bodies, whose brief history is in addressing public health issues, appear to be showing a natural inclination to tackle the larger acute health issues.

The Practical Assistance Offered to Commissioners.

28. Epilepsy Action provides a collection of commissioning resources to support commissioning discussions and help evidence how services meet commissioning targets.

29. Epilepsy Action’s Commissioning Advocates scheme trains and supports local members to get involved with local service development opportunities. Opportunities to roll this out across all 211 CCGs are limited for the small epilepsy voluntary sector due to lack of funding. If the DH wishes to positively encourage engagement between individuals with health conditions and commissioners then funding to support this type of initiative is required.

30. We support the Quality Standards programme but the translation of Quality Statements into improved clinical practices needs development. Quality Statement 7 in the epilepsy Quality Standards relates to patient satisfaction with care planning. Only 14 % of people with epilepsy report having a care plan.\(^{377}\) This shows the divide between the theory and reality. There is scope for this Statement to become a Patient Reported Experience Measure (PREM) or a Commissioning for Quality and Innovation Measure (CQUIN), but this would require local initiative and will lead to sporadic implementation (if at all).

31. The Adult Social Care Outcomes Framework places emphasis on improving the quality of life and sustaining the independence of people with dementia. We would like to see the scope of this Framework extended to other long term conditions (such as epilepsy) that feature proportionately high in social care settings, and impact significantly on peoples’ quality of life.

\(^{374}\) Health-E mum to be, Epilepsy Action, 2013. http://www.epilepsy.org.uk/healthenum-to-be


CURRENT EXAMPLES OF EFFECTIVE INTEGRATION

32. In East Kent a community Epilepsy Nursing Service was commissioned to provide epilepsy assessments, advice, support and monitoring of medication changes to improve the quality of life of patients.

33. ESNs refer into the community matron service and undertake joint visits as required. They also work alongside the community service medicines management team, who will support patients in their own home with medication adherence, and sometimes do joint visits with them.

34. All patients receive a written care plan, which they sign to indicate that they have been actively involved in devising it, at the time of their appointment. Patients are encouraged to share their care plans with other relevant professionals.

35. This is important to ensure a safe, integrated service, and regular audits are used to check that correspondence is being received promptly. Commissioners monitor the waiting times with an agreed action plan to focus on improving in specific areas. The “did-not-attend” rate in East Kent has fallen from 24% to 1.6% as a result.

36. Talking to families who have a dependent with severe epilepsy, it is clear that better integration between health and social care would make a huge positive difference to the accessibility of care and support. Unfortunately too often we hear that families were very close to “breaking point” before they were able to access any care and support. The reason for this is opaque signposting and accessibility methods. There was also:

— An assumption that health and social care were already integrated.
— An expectation that hospital consultants would automatically refer those eligible for care and support to the correct department (as families’ primary contact with the system was their consultant). When some families have tried to access support, they were only told about welfare benefits.

37. Improving the pathway for referral to social care needs assessments within health departments would greatly improve the lives of many people with long term conditions and their carers. More straight-forward access, improved timing of access, clearer information about costs and the availability of direct payments should also be aims of an improved system.

38. Examples:

(a) Family of a 15 year old girl with Rhett Syndrome. “We have recently been appointed overnight NHS carers a couple of nights a week for our 15 year old daughter who has up to 10 generalised tonic clonic seizures a night. It allows me to at least get 2 full nights of sleep a week!”

(b) Family of a 17 year old girl with 100 plus seizures a day. “If you have a consultant paediatric neurologist and a social worker get on to them! Tell them you need help and support, tell them you’re at crisis point, because there will be help there. If you don’t tell them they don’t know you need the help! Unfortunately the help doesn’t just happen YOU have to get onto it! Over the years caring for her day and night and 100+ seizures a day, I had to shout loud to her consultant neurologist to get help in place. This came in the help of respite from children’s hospices, and direct payment for carers.”

(c) Individual who lives alone and has “severe epilepsy” and couldn’t afford to pay his carer. “I had a carer for a while, it really helped me to socialise and get out of the house—get a little more independence. She helped with showering, cooking, ironing and shopping too. I wasn’t working and claimed sickness benefit and Disability Living Allowance to live on. I had to use my benefits to pay £300 per month for the service. It wasn’t until I could no longer afford to pay for a carer that I was told about direct payments, and that if my social worker had set up direct payments I might have had to contribute less of my benefits towards paying her.”

THE IMPLICATIONS OF AN AGEING POPULATION

39. The over-65s are the largest group in which a first seizure is reported.\(^{378}\)

40. We are only aware of one geriatrician with a declared specialist interest in epilepsy operating in the UK. Only 13% of geriatricians that treat patients with epilepsy reported receiving training on epilepsy management.\(^{379}\) Of those who have not attended a course, 85% of them regularly see epilepsy patients.\(^{380}\) This is despite epilepsy growing in prevalence as we live longer and demographics shift.

41. Accurate identification of epileptic activity and treatment among older age groups is a concern, with the symptoms of epilepsy often misinterpreted as part of other age related conditions, or attributed to the aging process. Higher rates of co-morbidities and living alone, means that care and support needs are high in this demographic, particularly in terms of preventing or delaying critical needs.


\(^{379}\) Epilepsy Action, Epilepsy amongst older people: experiences and perceptions of geriatricians. Research conducted by MORI, April-May 2005.

\(^{380}\) Epilepsy amongst older people: experiences and perceptions of geriatricians. MORI, Epilepsy Action, 2005.
42. Care pathways for older people reporting a first seizure are complex, services fragmented and the range of expertise patients need is not often available in a single setting.\textsuperscript{381} Too often we believe service availability is discriminatory towards older people with the condition, where inclination is to refer to geriatric services rather than specialist neurological services. Too often older people with epilepsy are proved with a standard of treatment that would not be deemed acceptable to a younger person with the same diagnosis.

**THE INTERACTION BETWEEN MENTAL HEALTH**

43. Depression is the commonest comorbid psychiatric condition in epilepsy. A Canadian population based study put this figure at a lifetime prevalence of 24.4%, compared a general population figure of 13.2%.\textsuperscript{382}

44. The screening and identification of people with epilepsy who may be experiencing depression or mental health issues is currently poor. The processes governing annual reviews depend on where a person lives, and referrals between neurological and specialist mental health services are weak. The Improved Access to Psychological Therapies (IAPT) programme has been targeting those people with a long term condition who may be at higher risk of psychological illness. This clearly applies to people with epilepsy (as a cohort) but we have seen no signs that more people with epilepsy are being referred to psychological services as a result.

**THE EXTENT TO WHICH PATIENTS**

45. Only 14% (128/947) of people with epilepsy report having a written care plan.

46. Various UK and international studies have shown the benefits of care planning, properly executed with the involvement of both patient and multi-disciplinary team and implemented through a targeted strategy.\textsuperscript{383} Quality of life benefits include patient and family satisfaction and reduced stress, anxiety, and depression.\textsuperscript{384,385,386}

47. Over a third (37%, 305/827) of patients (adults and children) were not offered an epilepsy review in the last twelve months. Of adults, 68% (206/305) were still having seizures. Review programmes are not comprehensive, those in greatest need of a review are not receiving one.

9 May 2013

**Written evidence from Parkinson’s UK (LTC 58)**

1. **INTRODUCTION**

1.1 Parkinson’s UK welcomes the opportunity to participate in this inquiry into long-term conditions. This issue is particularly relevant to us due to the nature of Parkinson’s which is a long term, progressive and incurable condition. Although Parkinson’s can be well-managed with medication and treatment, there is no prospect of a person’s condition improving over time, and there is no cure.

2. **TREATMENT OUTSIDE HOSPITAL**

2.1 Parkinson’s is an extremely complex condition. A wide range of therapeutic interventions are required to support people to remain independent and to maintain their quality of life for as long as possible. One study found that people with Parkinson’s require input from up to 25 specialists.\textsuperscript{387} However, there are huge gaps in provisions of these services across the UK. The APPG on Parkinson’s report in 2009 revealed major inequalities across the whole of the UK in access to care services for people with Parkinson’s.\textsuperscript{388}

2.2 Parkinson’s nurses are a local source of expert knowledge and can provide valuable help in supporting people coming to terms with their Parkinson’s diagnosis as well as offering guidance on managing medication and making appropriate referrals. Parkinson’s UK has found that the provision of a single Parkinson’s nurse can provide an average annual saving of £43,812 in consultant appointments, £80,000 in avoided hospital admissions and £147,021 in avoided overnight stays in hospital.\textsuperscript{389}

2.3 Another key element to providing integrated care for people with Parkinson’s is the development and use of a personal care plan designed to meet their specific needs. However, a study has revealed that only 22%
of people with neurological conditions receive a personal care plan. Although the Government has cited research claiming 70% of people with long-term conditions did not want a written care plan, we believe that this would improve the standard of care for Parkinson's. Therefore, we would like to see everyone with Parkinson's with have a care plan that is drawn up in collaboration with them and is then implemented and regularly reviewed.

2.4 NHS continuing health care is a package of funded care for people with a "primary health need"—it should be a mechanism for providing personalised services for people with long-term health conditions. For people with Parkinson's, the need for NHS continuing health care tends to come at an advanced stage of the condition. In practice, people applying for NHS continuing health care often experience delays, difficulties in accessing it and distress at a time when they are coping with managing their condition. Worryingly people with Parkinson's (and other long term conditions) end up using the means tested social care system instead to get the support that they should be getting through the NHS. This is extremely concerning to us and one of the reasons why the APPG on Parkinson's is currently holding an inquiry into NHS continuing health care.

3. READINESS TO TREAT LONG-TERM CONDITIONS IN THE COMMUNITY

3.1 Cost-shunting between the NHS and social services can make it extremely difficult for people with Parkinson's to receive holistic, integrated care. We hope that the advent of Health and Wellbeing Boards (HWBs) will provide and opportunity for health and social care to work in a more integrated way for people with long term conditions; however whilst one system is means tested and the other is free at the point of delivery, it is difficult to imagine how true integration will be actualised.

3.2 In order for people with Parkinson's to receive community-based care, it is important that they have access to the appropriate professionals. A survey conducted by Parkinson's UK in 2011 revealed that 27% of Parkinson's nurses were being asked to stop home visits and take on more general nursing duties on the wards to fill in gaps created by other nurse posts. We also have evidence that people sometimes find it difficult to access appropriate therapists, particularly speech and language therapists.

3.3 Another key element that can support the treatment of long-term conditions in the community is the information and support provided by voluntary sector organisations. In the case of Parkinson's UK, this information and support includes information about managing the condition, self-care programmes and the provision of peer support networks. However, we are aware that not everyone with long-term conditions is aware that this support is available to them. Parkinson's UK feels that this is a missed opportunity to better support the care of long-term conditions when patients are in a community setting. We would like to see better signposting from health and social care professionals to these sources of information and support.

4. ASSISTANCE TO COMMISSIONERS

4.1 The advent of the new NHS means decision making about services for people with Parkinson's will fall to clinical commissioning groups (CCGs). CCGs must have the appropriate skills and understanding in order to commission neurology. This is particularly important with less common conditions such as Parkinson's and clinical commissioning groups may not have had much experience of such conditions before.

4.2 We recognise that support to commissioners is really important which is why we set up (with our partners MS Society, Motor Neurone Disease Association and Epilepsy Society as an affiliate member), Neurological Commissioning Support (NCS) who work with commissioners to map neurology services and analyse identified gaps. Working with the commissioners, NCS can then help to develop solutions to develop appropriate services. One example of this is the specific integrated care pathway for Parkinson's developed by NCS. The pathway, which covers primary, secondary, tertiary and social care ensures integration of health and social care with the user at the centre of the decision making process. The aim is to support commissioners and service providers to improve quality of care for neurological conditions in a cost-effective way.

5. EXAMPLES OF EFFECTIVE INTEGRATION

5.1 Parkinson's UK believes that better integration across health and social care would result in a higher standard and quality of care for people with Parkinson's and other long-term conditions.

5.2 A good example of this is the work that Neurological Commissioning Support, has developed as described in section 4. Neurological Commissioning Support takes an integrated approach to both assessing services in a local area and to devising solutions to developing new services and care pathways.

5.3 The use of Parkinson's nurses can result in a more integrated and cost-effective approach to supporting people with Parkinson's by working with health and social care professionals and referring people on.

5.4 Our own Information and Support Workers (ISWs) are another example of effective integration. As well as working with both health and social care providers across the UK, our ISWs also provide emotional support

390 Fitzpatrick, Ray et al (September 2010) The needs and experiences of services by individuals with long-term progressive neurological conditions and their carers. A benchmarking study University of Oxford

391 Lords Hansard, January 8 2013, Column WA50

392 Parkinson’s UK (2011) Protect Parkinson's nurses in England and save the NHS money
to people with Parkinson’s and their families, as well as assistance with other issues such as applying for benefits.

6. Implications of an Ageing Population

6.1 As Parkinson’s is a condition that predominantly affects older people, the impact on service provision for an ageing population is of particular concern to Parkinson’s UK. Parkinson’s UK has conducted research that predicts an increase of 28% in the number of people with Parkinson’s in the UK by 2020. This will mean that there will be approximately 162,000 people in the UK living with Parkinson’s by 2020.393

6.2 We already have concerns that the existing levels of provision of services for people with Parkinson’s are not sufficient to meet current needs. One example of this is the workload of Parkinson’s nurses. The current NICE guidance recommends that the average caseload of a Parkinson’s nurse is 300 patients per nurse.394 In 2011, Parkinson’s UK surveyed Parkinson’s nurses in England and found that 19% of them had caseloads of over 700 patients.395 This caseload limits their capacity to provide appropriate care to all Parkinson’s patients at the current numbers.

7. Mental Health Conditions

7.1 The interaction between mental health conditions and long-term physical conditions is particularly pertinent to people with Parkinson’s, as the impact is not always recognised and the effects can be severe. There are different factors that link mental health problems and Parkinson’s: it can be part of the condition, for example changes to the chemicals in the brain that are part of Parkinson’s could also cause depression and anxiety; mental health problems can be caused by the difficulties of living with Parkinson’s, for example not being able to move can make people more anxious and may even cause panic attacks; Parkinson’s medication can have side-effects including psychosis and compulsive behaviours.

7.2 Dementia is also common and one in three people with Parkinson’s have some form of dementia and up to 80% of people with Parkinson’s may develop dementia.

7.3 The impact of these mental health conditions can be severe for people with Parkinson’s, which can include getting into debt, experiencing marriage breakups or even being arrested as a result.

7.4 In 2007 we surveyed 13,000 members396 and their responses show how widespread the experience of mental ill health is for people with Parkinson’s. In the month before the survey:
   — 58% of people had felt depressed.
   — 45% of people had felt anxious, frightened or panicky.
   — 37% of people difficulty concentrating or staying focussed.
   — 63% of people had problems with concentration.

7.5 Access to treatment for mental health problems is poor. Only 11% of people with Parkinson’s have seen a mental health professional which is the lowest of any therapeutic input for Parkinson’s.

8. Personalised Services

8.1 With regards to personalised services, it’s encouraging that those receiving NHS continuing healthcare will soon be able to access a personal health budget (from 2014). Parkinson’s UK would like to see the option of personal health budgets being made more available to people with Parkinson’s and those with other long term conditions. The success of the budgets will of course be reliant on the availability of locals support and services and good care planning with the user at the centre of their care.

9. Other Issues of Concern

9.1 The inquiry covers many of the issues associated with the care of long-term conditions in the terms of reference but there are additional issues that are particularly relevant to the treatment and support of people with Parkinson’s, which we have briefly detailed below.

9.2 Neurological services have tended to be of low priority within the NHS, resulting in patchy levels of provision and poor support for patients. A report from the National Audit Office in 2011 found neurology services were fragmented and poorly coordinated. Worryingly, emergency hospital admissions had increased by 32% between 2004–05 and 2009–10, compared to 17% for the NHS as a whole.

9.3 Their concerns were echoed by the Public Accounts Committee in their report in 2012.397 The committee highlighted that, despite the introduction of the National Service Framework (NSF) for Long-term Conditions, it had not improved standards of care and that neurological care lagged behind priority areas such as cancer.

393 Parkinson’s UK (2009) Parkinson’s prevalence in the United Kingdom
395 Parkinson’s UK (2011) Protect Parkinson’s nurses in England and save the NHS money
396 Parkinson’s UK (2008) Life with Parkinson’s today—room for improvement
397 Commons Public Accounts Committee (2012) Services for people with neurological conditions
and stroke. PAC made a number of recommendations, including: a National Clinical Lead for neurology; local neurological networks coordinated by the NHS; access to a care plan for everyone with a neurological condition, covering both health and social care; the department mandating joint health and social care commissioning; and the development of a generic quality standard for neurological conditions.

9.4. Progress has been made with some of the PAC recommendations, for example, a clinical director has been appointed and strategic clinical networks covering neurology are currently being set up. However, we are still awaiting the development and publication of the NICE quality standard for Parkinson’s and the quality standard for neurological conditions. The updated NICE guideline for Parkinson’s is now long overdue.

9.5. The lack of neurological indicators and outcomes in the NHS commissioning outcomes frameworks are also of serious concern to us. There is a real danger that commissioners will focus on the targets that are set by the COF indicators and not engage with those indicators that are cross-cutting and more difficult to demonstrate.

10 ABOUT PARKINSON’S UK

10.1 Every hour, someone in the UK is told they have Parkinson’s. One in 20 is under the age of 40. There are approximately 127,000 people with Parkinson’s in the UK.

10.2 We bring people with Parkinson’s, their carers and families together via our network of local groups, our website and free confidential helpline. Specialist nurses, our supporters and staff provide information and training on every aspect of Parkinson’s.

10.3 As the UK’s Parkinson’s support and research charity we’re leading the work to find a cure, and we’re closer than ever. We also campaign to change attitudes and demand better services.

10.4 Parkinson’s is a progressive neurological disorder for which there is currently no cure. It is associated with the death of nerve cells in the mid-brain which results in the loss of the chemical messenger dopamine. This affects learned voluntary movements such as walking, talking, writing and swallowing. As the condition progresses it impacts on all aspects of the person’s life and the lives of those around them.

10.5 As well as the symptoms that affect movement, people with Parkinson’s can find that other issues, such as tiredness, pain, depression and constipation, can have an impact on their day-to-day lives.

9 May 2013

Written evidence from the British Specialist Nutrition Association (LTC 59)

The following response has been submitted by the British Specialist Nutrition Association (BSNA) Ltd. The BSNA is the trade association representing manufacturers of products designed to meet the nutritional needs of individuals at different life-stages or with specific health requirements. BSNA members include companies that manufacture gluten-free foods which are reimbursed on prescription for sufferers of coeliac disease.

1. SUMMARY

The BSNA welcomes the Health Select Committee’s inquiry into the management of long term conditions given their prevalence and significant impact on health service budgets in England. This response deals with the diagnosis and management of coeliac disease on the NHS. We would welcome the opportunity to discuss these issues with you in more detail and answer any questions you may have.

The BSNA is the trade association representing manufacturers of products designed to meet the nutritional needs of individuals at different life-stages or with specific health requirements. BSNA members include companies that manufacture gluten-free foods available on prescription for sufferers of coeliac disease including: Dr. Schär, Juvela and Warburtons. The BSNA wishes to work with the Department of Health (DH) and with Clinical Commissioning Groups (CCGs) to create a sustainable solution for coeliac disease sufferers to continue to access staple gluten-free foods on prescription.

EXECUTIVE SUMMARY

1.1 Coeliac disease is a long term, autoimmune condition triggered by intolerance to gluten, a protein found in wheat, rye and barley. Around 1 in 100 people in the UK are affected, although only 10–15% of those with the condition are diagnosed.

1.2 Coeliac disease is not “curable”; the only treatment is adherence to a strict gluten-free diet. There is no medical intervention or alternative treatment programme. Without proper management, coeliac disease can lead to a greater incidence of chronic conditions including osteoporosis and cancer, placing unnecessary strain on health services.

1.3 Management of coeliac disease can be delivered effectively in the community; with areas of England pioneering pharmacy led prescribing schemes that reduce the impact on primary and secondary care.
1.4 A clearer patient pathway and earlier diagnosis would speed up the proper management of coeliac disease and reduce the health complications associated with it.

1.5 Coeliac UK, the national charity working for people with coeliac disease, have developed national guidelines for the prescribing of gluten-free foods exist recommending basic unit allowances and appropriate staple products for prescription such as fresh bread and pasta. However, contrary to these guidelines, restrictions to the basic unit allowance as well as types of staple products prescribed have been imposed in various parts of the country. Those with coeliac disease greatly value the provision of gluten-free foods on prescription and have strongly indicated their opposition to unfair restrictions or barriers to access.

1.6. The BSNA believes that the provision of an essential gluten-free prescription provides good value, fosters good dietary adherence, and, in the long-term, will help save the NHS money.

2. ABOUT COELIAC DISEASE

2.1 Coeliac disease is an autoimmune disease which affects 1 in 100 people in the UK. For people with the condition, the consumption of gluten triggers an immune reaction, making the body attack itself. Eating gluten damages the lining of the small intestine and affects a patient's ability to absorb nutrients from food properly.

2.2 Coeliac disease is a life-long condition, the only treatment for which is adherence to a strict gluten-free diet. Coeliac disease requires on-going review and management.

2.3 Coeliac disease isn’t an allergy or an intolerance to gluten. In cases of coeliac disease, the immune system mistakes substances found inside gluten as a threat to the body and attacks them.

2.4 Diagnosis times for coeliac patients average around 13 years as symptoms are commonly mistaken for other gastrointestinal disorders such as Irritable Bowel Syndrome (IBS). For a diagnosis of coeliac disease to be confirmed, patients need to undergo a small intestinal biopsy, although in certain instances children displaying symptoms can be put straight onto a gluten-free diet following blood tests.

2.5 The main health risks linked to untreated and poorly managed coeliac disease include deficiencies of essential nutrients, leading to conditions such as anaemia; osteoporosis and associated increased risk of fractures due to a lack of calcium; it can lead to the development of bowel cancer and in women it can also cause infertility and adverse outcomes in pregnancy.

2.6 The NICE 2009 guidelines state that “coeliac disease can be very effectively treated with a gluten-free diet. It is important to identify people with the undiagnosed disease so as to provide satisfactory individual treatment and also to improve the overall health of the community.”

3. THE NEED FOR GLUTEN-FREE FOODS ON PRESCRIPTION

3.1 It is vital for people with coeliac disease to be able to access basic gluten-free foods, including fresh bread, on prescription. Adhering to a strict gluten-free diet is the medically advised treatment for coeliac disease. Choice is not an option as deviation from the diet will have a direct effect on health and morbidity.

3.2 National prescribing guidelines titled “Gluten-free prescribing: a revised guide 2011” which provides information on the recommended amounts and type of products available to coeliac patients on prescription was produced by the NHS and endorsed by Coeliac UK, the Primary Care Society of Gastroenterology and the British Dietetic Association. It highlights the importance of adherence to a gluten-free diet in order to minimise the risk of associated complications and reflects current guidance on the prescribing of gluten-free foods.

3.3 Specialist gluten-free foods have been developed and made available on prescription to replace everyday starchy foods such as breads, flour, pasta and cereals. Prescription gluten-free food products are approved by the Department of Health’s Advisory Committee on Borderline Substances (ACBS). Only essential gluten-free foods which contribute to a healthy balanced diet are approved for availability on prescription.

3.4 Prescription gluten-free products are specifically selected to provide a guaranteed supply of essential staple foods, which should provide around 15% of patients’ energy requirements.

3.5 Patients can purchase gluten-free products including pastas and flour in certain larger supermarkets however these are often priced significantly higher than gluten-containing alternatives. This cost disproportionately affects people on lower incomes and those who live in more rural areas with little or no access to larger stores.

3.6 The social and psychological impact of sticking to a life-long gluten-free diet is significant and, if managed inappropriately, may result in further hidden costs to the NHS including repeated visits to the GP, further investigations and related prescription costs.

http://www.coeliac.org.uk/sites/files/coeliac/a5_prescribing_guidelines_hires_for_print_and_web_april_12_2.pdf
3.7 The annual ingredient cost in England of the 2012 provision of ACBS approved gluten-free foods was approximately £26.8 million Prescription Cost Analysis England 2012, NHL Information Centre, April 2013. Since the net ingredient cost for all prescriptions in England was £8.53 billion, gluten-free foods comprise only 0.31% of the total net ingredient cost for all prescribed products.

4. VARYING PRACTICE ACROSS THE NHS

4.1 Restrictions have been introduced by a number of Clinical Commissioning Groups (and formerly PCTs) on cost rather than clinical grounds and run contrary to national guidance (as discussed above) developed by the patient group Coeliac UK. The Government publically stated support for coeliacs to have access to such products on the NHS.

4.2 The decision to withdraw patient access to a staple gluten-free food such as fresh bread conflicts with national guidance developed by the patients’ organisation Coeliac UK, as well as the Government’s publically stated support for coeliacs to access such staple products on prescription.

4.3 Within the new NHS, CCGs should operate on a level playing field to provide access to essential staple gluten-free foods such as bread and flour on prescription, to allow those with coeliac disease to successfully manage their own condition.

4.4 The transition to CCGs has made it more difficult to understand the policies being operated in different areas in the UK.

5. IMPACT OF RESTRICTIONS ON PATIENTS

5.1 Responding to a recent BSNA survey, over eight in ten (86%) people with coeliac disease agreed that accessing gluten free foods on prescription was important in aiding adherence to a gluten-free diet. The survey indicated that the poorest rely more heavily on prescriptions to manage their condition, and appeared to have fewer options available to them.

5.2 Two-thirds of those who had had their prescriptions limited or stopped reported a negative impact on their ability to manage their condition. One third of those surveyed said that cuts had made it more difficult for them to access gluten-free foods whether on prescription or in shops.

6. SUPPORTING THOSE WITH COELIAC DISEASE

6.1 Clinically led NHS services for the diagnosis and management of coeliac disease can be delivered through a variety of routes including the acute care setting, community pharmacy and primary care practices.

6.2 Following diagnosis of coeliac disease or dermatitis herpetiformis (DH), it is essential that referral is made to a dietitian for expert advice on following a gluten-free diet that is tailored to the individual.

6.3 Coeliac UK, the national charity supporting people with coeliac disease, offers help and support to those diagnosed. It supports the move towards increasing pharmacy-led prescribing schemes and encourages those diagnosed with coeliac disease to see dietitians to help manage their condition. A dietitian can give individual advice and a step by step plan on how to remove gluten from the patient’s diet.

7. MANAGING COELIAC DISEASE THROUGH INTEGRATED CARE

7.1 Regular review is part of the foundation of support for promoting good adherence to a gluten-free diet. Integrated care is also essential to the foundation of support.

7.2 New more cost effective care pathways are currently being developed which will place primary care at the centre of on-going care for coeliac patients.

7.3 Public Health England recently published its priorities for the year 2013–14 which included a commitment to “reducing the burden of disease”. Local Health and Wellbeing Boards are looking to focus on strategies which manage conditions and reduce the likelihood of future illness. Easy and widespread access to gluten-free food for coeliac patients is an example of this type of policy as it is the only way to help those with coeliac disease to overcome their symptoms and reduce the risk of associated long-term complications. The BSNA will look to work with Local Health and Wellbeing Boards to becoming good advocates for managing conditions.

401 Restrictions still exist in Middleton and Rochdale; Telford and Wrekin; Greenwich; Stockport; Oldham; Manchester; Suffolk; Leigh and Wigan.
402 “The aim of providing gluten-free food products on NHS prescription is to encourage patients with coeliac disease to stick to a gluten-free, nutritious diet so they do not go on to develop more serious illnesses, which can affect their quality of life as well as being much more costly for the NHS,” Andrew Lansley Health Secretary May 2012
403 Opinion Leader conducted an online survey of 1,000 Coeliac Disease patients, parent and carers between February 4th and February 25th 2013. The sample was obtained from customer lists supplied by gluten-free food manufacturer, Dr Schär. The list was filtered to target those in the twenty PCT/CCG areas of interest, listed above. Data are Unweighted.
Dieticians

7.4 Community based specialist dieticians would be ideally placed to offer patients clinically led support in the community.

7.5 Given the importance of a gluten-free diet in the treatment of coeliac disease, Coeliac UK has set out steps to setting up a dietitian led coeliac clinic. Diet is essential in the management of patients with coeliac disease and a dietitian is best placed to provide support and advice on individual nutritional requirements.

Pharmacy-led prescribing schemes

7.6 Pharmacy led schemes can help improve compliance and diagnosis as they are more accessible to a greater number of people with coeliac disease.

7.7 Pharmacy-led prescribing schemes see patients initially assessed by a dietician who will then assign them a recommended number of units of gluten-free foods required for a balanced diet. Once assessed under the scheme, community pharmacists are provided with a list of prescribable products from which patients can order up to the number of units that they are entitled to each month. The number of units is based on national guidance available from Coeliac UK.

7.8 Schemes have been introduced in Bedfordshire, Cornwall and the Isles of Scilly, Cumbria, Derby, Northamptonshire, South West Essex and Tayside in Scotland. There are plans for such schemes to be rolled out across the whole of Scotland and in Wales.

7.9 Coeliac UK has produced a toolkit for Commissioners advising on the provision of gluten-free foods, which aims to support commissioners in developing a cost-effective, enhanced service through pharmacy-led prescriptions for patients with coeliac disease.

7.10. Through the use of a pharmacy-led supply schemes, gluten-free foods are supplied directly from community pharmacists, thus minimising the workload for GP practices. A review of established schemes in Northamptonshire and Cumbria shows savings of between 20% and 40%. If this approach was applied nationally, there is the potential to save between £5 and £11 million per year in England alone, as well as freeing up GP time.

7.5 The potential benefits of changing to pharmacy-managed supply of gluten-free foods include:

— improved dietary compliance and health outcomes, since some patients currently do not receive prescribed foods, when it is known that access to prescriptions is the single most important factor in helping adherence to the gluten-free diet;

— release of clinical time (saving of 209,000 appointments or over 20,000 hours of GP time according to a 2002 RCGP estimate), which could be used for better management of patients with coeliac disease after diagnosis;

— prevention of overprescribing by application of the 2011 revised guidelines on appropriate consumption of gluten-free foods;

— better cost control as more people with coeliac disease are diagnosed over the next few years. Currently it is estimated that only 10—15% of people with coeliac disease are diagnosed;

— dissemination of the 2009 NICE guidelines combined with improved GP training and awareness of coeliac disease should result in increased diagnosis

— improvement in patient experience by creating a more flexible service; and

— increased patient choice.

9 May 2013

Written evidence from Terrence Higgins Trust (LTC 60)

1. HIV is now a long term condition affecting over 100,000 people in the UK. The number of people living with HIV has trebled in the last ten years. It is therefore necessary to find innovative, more cost-effective ways of delivering HIV care.

2. Terrence Higgins Trust supports models of care and support that would deliver savings to the NHS and meet growing demand for services. These include greater provision of basic HIV care in primary care settings and use of Internet and peer support services, such as our Life Plus service.

3. In order to provide routine care for people with HIV and also as a result of the withdrawal of specialist HIV social care, mainstream health and social care services need to be better informed about HIV, in order to deliver appropriate care and avoid cases of discrimination.


405 http://www.coeliac.org.uk/Gluten-freesupplytoolkit

4. There is a strong association between HIV and mental ill health. Mental ill health can be a result of HIV, but is also exacerbated by financial, social and other personal difficulties. It is also a cause of poor treatment adherence among people with HIV. Psychological and other support should therefore be prioritised in order to support both physical and mental health.

5. The over 50s are the fastest growing group of people with HIV in the UK. This group reports twice as many other long term conditions as their peers, and significant anxiety about the readiness of primary and social care services to treat them effectively and without discrimination.

**INTRODUCTION**

1.1 Terrence Higgins Trust is the UK’s largest HIV and sexual health charity, with 32 service centres across the UK. We are a campaigning and membership organisation which advocates on behalf of people living with or affected by HIV or poor sexual health.

1.2 We provide services for people living with HIV to manage their condition and access emotional and practical support. These include one-to-one counselling, peer support groups, health trainers and information and advice covering benefits, housing, finances, employment and immigration. We also deliver community based clinical services, such as chlamydia screening and rapid HIV testing, and health promotion campaigns and initiatives which target populations most at risk of HIV and poor sexual health.

**BACKGROUND TO HIV AS A LONG TERM CONDITION**

2.1 Since the introduction of highly active antiretroviral therapy (HAART) in the mid 1990s, HIV has changed from being a terminal illness to a long term manageable condition for most people. However, there remains a substantial need for care and support, particularly for those diagnosed late, those who acquired the virus before the availability of HAART, those unable to manage their treatments or those with a more complex set of social and health problems. In addition, people with HIV are typically challenged by significant levels of stigma and uncertainty about their prognosis.

2.2 There have been a number of developments in recent years which present new challenges for the long term support and care of people with HIV in the UK. These include:

- increasing longevity of people with HIV as treatments improve;
- increasing levels of comorbidities as people age with HIV;
- steadily increasing numbers of people with HIV in the UK. There are now over 100,000 people with HIV in the UK—three times as many as there were ten years ago;
- increased understanding of the long term impacts of HIV including financial and social exclusion, poor mental and physical health;
- a sub-section of people with HIV who have no recourse to public funds;
- reductions in both mainstream and HIV specialist social care provision by local authorities;
- increasing use of mainstream care and support by people with HIV as specialist provision reduces; and
- persistent levels of stigma and poor understanding of HIV amongst some mainstream services and the general public.

**TREATING PEOPLE OUTSIDE OF HOSPITAL**

3.1 Given the rising number of people living with HIV, there is a need to review how HIV treatment is delivered, as there will eventually be insufficient capacity within the existing services structure. Pressure on specialist services is further exacerbated because GPs often refer patients with HIV to their HIV clinic for non-HIV related health problems. This is due to a lack of knowledge and understanding among many GPs. This is unnecessarily costly and can also deny people with HIV the access to GP expertise. Care for people with HIV must therefore be included in training and guidance for new and existing primary care staff.

3.2 Routine aspects of HIV care could also be delivered in primary care settings away from specialist centres. This would increase capacity in specialist services, create savings for the NHS and bring care closer to the patient. There are currently around 33 specialist HIV treatment providers in London alone. A movement towards greater primary care involvement in HIV care would also allow for the development of centres of excellence which could concentrate on highly specialist and in-patient HIV care and could be fewer in number.

3.3 Terrence Higgins Trust is innovating to provide more care for people living with HIV in their homes and communities. We are running a pilot project called One Clinic in London, which provides nurse-led HIV care in GP practices. One Clinic is a two-year project which provides HIV care for those patients on treatment whose condition is stable and have an undetectable viral load. Patients can have their medication prescribed and their bloods monitored by a nurse in a GP clinic at more convenient times and locations for them, and avoiding the costs of hospital-based services, which are freed up to support patients with more complex needs. The NHS could do more to support this model of care for people with HIV and other long term conditions.
3.4 The Government could also support national initiatives that use the knowledge and support that can be provided between patients with particular conditions. Terrence Higgins Trust’s innovative LifePlus service, which has been funded by the Elton John AIDS Foundation, helps people living with HIV to manage their condition and reduces healthcare costs. It is a model that central government could support for various conditions as a low-cost way of improving long term condition management.

3.5 The main components of the LifePlus service include:

— MyHIV.org.uk—a website with interactive tools and information to help people better understand and manage their HIV.
— Online support and counselling through interactive chat with qualified professionals.
— Peer support through the MyHIV community forum where people can share personal learning and experiences of living with HIV.

3.6 Health Trainers offer support and information in areas that clients or clinic staff have identified. Health Trainers can support making sense of a diagnosis, managing side effects, sex and relationships, understanding medication, how to get the best out of talking to medical staff as well as diet and nutrition. Support can be accessed over the phone or by email.

3.7 In two years, MyHIV became the largest national network of people with HIV. 10% of people accessing HIV care already use the service and support each other via MyHIV. Users report high levels of satisfaction, with 88% stating that they are now better able to manage their HIV and 93% reporting better knowledge of HIV thanks to the service.

The Readiness of Existing Services

4.1 Research into the experiences of people living with HIV when using health and social care services has uncovered a number of concerns, particularly in relation to knowledge of HIV and in some cases discriminatory practices among social care workers, GPs and other healthcare professionals. As the number of people living with HIV continues to rise, it is increasingly important that these problems are addressed.

4.2 UK research suggests that people with HIV most commonly experience discrimination when accessing public services, with health and dental services being a particular area of concern. A 2008 survey of people with HIV in London found that one third of people encountered discrimination because of their HIV status. Of those reporting discrimination, half said it had come from a healthcare worker: 26% from a dentist, 18% from a GP and 10% from hospital staff. The Readiness of Existing Services

4.3 Until 2010, funding for HIV social care was protected by the ring-fenced AIDS Support Grant (ASG). The removal of this ring-fence in 2010–11 has already led to defunding of HIV social care, and this is worsening as Local Authorities’ budgets come under increasing pressure.

4.4 As with healthcare, social care for people with HIV has traditionally been delivered through specialist services. As HIV has turned into a long-term condition, there is now a gradual withdrawal of these specialist services. However, mainstream social care services have not adapted to cater for the needs of people with HIV. It is again imperative that mainstream social care staff gain basic HIV awareness to be able to meet the needs of those service users. THT has experience of many situations where the current lack of training has caused discrimination against people with HIV from social care staff. People over 50 living with HIV also express concern that social care staff will lack the necessary knowledge of HIV to support them in old age.

4.5 Given that the public sector comprises some of the UK’s largest employers, it holds considerable potential not only to improve the delivery of services to people living with HIV, but also to increase HIV awareness and tackle discrimination. A great deal more could be done within the health service in particular in terms of training staff on HIV related stigma. Many health sector employees already receive HIV training from a health and safety perspective—but this does not look at the issue in the round and in some ways could be seen to exacerbate stigma by reducing HIV to an occupational hazard concern and thereby dehumanising the issue in the process. We would welcome a Government initiative, working in partnership with people living with HIV and representative agencies, to develop a robust campaign to challenge HIV stigma and increase awareness in public services.

4.6 Investing in strong self management programmes can also improve the situation by supporting people to be more confident and visible around their HIV status and assisting disclosure in key settings. The Equality Act (2010) gives people living with HIV some means of redress. However, taking legal action after discrimination has occurred is an arduous and potentially costly exercise. Reductions to the legal aid budget have reduced the capability for people living with HIV to take action against service providers, and this in turn devalues equalities legislation.

407 The People Living with HIV Stigma Index, November 2010
AGEING

5.1 Terrence Higgins Trust’s 50 Plus national study of people ageing with HIV discovered a range of particular challenges faced by people over 50 with HIV, including physical, mental, financial and social problems.

5.2 Compared with their peers, older people with HIV have twice as many other long-term health conditions. Only a third from our study reported they had no other long-term conditions, which contrasts sharply with the 57% of adults aged 45–74 in Great Britain who had none (Office for National Statistics, 2010). The most common conditions were high blood pressure, arthritis and neurological conditions. Heart disease and diabetes were also common. These conditions are associated with both the long-term effects of HIV treatment as well as ageing in general.

5.3 Again, many respondents to the study expressed anxiety about needing to use home care or residential care because of perceived, and sometimes experienced, prejudice and ignorance about HIV within these services. Providers of social care services to older people need to train their staff and define good practice in management of clients with HIV, while funders should ensure this is included amongst quality measures. Personalised care budgets could, again, drive change if older people used their purchasing power to choose HIV and gay-friendly providers.

MENTAL HEALTH

6.1 According to a recent study of over 2,000 people with HIV in UK, one in four had clinical depression. Unemployment, poverty and lack of a support system of friends and relatives are strongly associated with depressive symptoms. Perhaps unsurprisingly, patients with depression were less likely to be adherent and to have an undetectable viral load than other people in the study. Depression and other mental health issues have been linked to HIV treatment problems before but this is the first study to look specifically at the situation in the UK.

6.2 27% of respondents had a depressive disorder from the responses. Moreover, for 19% of respondents this was a major depressive disorder. 15% of employed people had symptoms, whereas 43% of those who were unemployed and 53% of those unable to work due to sickness or disability had symptoms. Those with enough money to cover basic needs reached 13% with depressive symptoms, but among those who said they only sometimes had enough money, 43% had symptoms. Those who could never cover their basic needs reached 53% with depression. There was also a clear relationship between degrees of social support and depressive symptoms.

6.3 The researchers also found an association between depressive symptoms and poor adherence to antiretroviral therapy. Among those saying that they had missed no drug doses over the past two weeks, 24% had depression. Among those who missed three or more doses, 42% were depressed. Increasing depression severity scores were associated with higher rates of detectable virus.

6.4 It is therefore important that psychological support is better prioritised as part of care for people living with HIV. It is equally necessary to address other underlying causes of mental ill health by providing social support and advocacy to address problems related to immigration, poverty, employment and discrimination. The complexity of issues faced by some minority groups affected by HIV, for example those caught up in or exiting the asylum system, requires a particularly coordinated approach. Services including welfare rights advice, employment support and immigration advocacy have been commissioned in the past by PCTs. As commissioning of HIV treatment and care has become the responsibility of NHS England, there is no clear home for these services within current commissioning arrangements and we are anxious that many will be lost and vulnerable people living with HIV will lose important sources of support, leading to a damaging impact on their mental and physical health.

9 May 2013

Written evidence from the Urology Trade Association (LTC 61)

EXECUTIVE SUMMARY

— Continence problems are an element in many long-term conditions, with many patients using urology devices such as catheters to help manage this issue. Clinicians need to be encouraged to consider associated issues, such as continence, which may arise from certain long-term conditions, and take proactive steps to assess their patients’ wellbeing in this area.


— Patients need to be able to access specialist advice to help them manage their conditions and choose the right products, and need to be able to access those products—often there are local restrictions in place which prevent this from happening, despite the national processes in place such as Part IX of the Drug Tariff.

— Both general clinical and procurement staff should be encouraged to improve their knowledge of continence care and the importance of patients being able to access appropriate levels of care, support and treatment products.

— There is a need for greater coordination between hospital and community care, particularly for individuals with long-term conditions who may have repeated admissions to hospital.

INTRODUCTION

1. The Urology Trade Association (UTA) represents up to 95% of manufacturers and service providers who supply the urology appliance market.

2. An estimated six million people in the UK are affected by continence problems. High quality urology appliances allow users to manage their conditions, maintaining their quality of life and independence and avoiding repeated medical consultations.

3. The UTA welcomes this opportunity to respond to this inquiry on Management of long-term conditions—our submission will look primarily at the following aspects of the inquiry:

   — The readiness of local NHS and social care services to treat patients with long-term conditions (including multiple conditions) within the community.

   — The practical assistance offered to commissioners to support the design of services which promote community-based care and provide for the integration of health and social care in the management of long-term conditions.

   — The ability of NHS and social care providers to treat multi-morbidities and the patient as a person rather than focusing on individual conditions.

   — The extent to which patients are being offered personalised services (including evidence of their contribution to better outcomes).

OVERVIEW—THE ROLE OF CONTINENCE CARE IN MANAGING LONG-TERM CONDITIONS

4. Incontinence can be a long-term condition in its own right, however people with a large number of medical conditions also need continence management to be integrated into their care—these include cancer, stroke, spinal cord injury, MS, spina bifida, Parkinson's disease and other neurological conditions. Therefore, there is a need to consider both how effective care is provided to deal with continence problems, and how continence is managed as part of other long-term conditions which mean that patients may have very complex needs.

5. The quality of care received by patients with continence problems has not always been high; this has implications not only for patients but also for public spending. For example, in September 2010, the Royal College of Physicians published the National Audit of Continence Care, which examined the quality of continence services in England, Wales and Northern Ireland. It identified a number of significant weaknesses in the care offered to patients and found that there is unacceptable variation amongst NHS Trusts in the type, quality and quantity of continence supplies made available to patients. There are a number of reasons why continence care might not be well managed.

6. Many patients require specific urology products to cope with dexterity and other impairments as well as for their comfort, wellbeing and lifestyle needs. While the differences between products may not be obvious to non-users, small differences can cause discomfort, difficulties in independent use, and an increase in urinary tract infections. This means that patients with the wrong product may need to rely more on carers or may be less able to work or maintain a social life.

7. A lack of knowledge among healthcare professionals who interact with patients, particularly GPs and community nurses, of the available products and the differences between them means that some professionals find it hard to recommend a product suitable for the needs of their patient. Specialist continence nurses are able to provide more specific advice and support, but not all patients are referred to these professionals.

8. Individuals should be able to access any product listed on Part IX of the Drug Tariff (the new arrangements under Part IX of the Drug Tariff for the provision of stoma and urology appliances, and related services, in primary care was published in 2009 following three years of consultation and came into force in April 2010). For items to be included on the Drug Tariff, they must be safe and of good quality; be appropriate for GP and, if relevant, nurse prescribing; and be cost effective. However, patients often have their choice restricted in a misguided bid by commissioners to save money.

9. Some PCTs introduced formularies which restrict the choice of products available with the aim of saving money—while it is not yet clear how many of these lists will be carried over by CCGs, the increasing pressures on the NHS budget have led to concerns that CCGs will continue to look to save money in this way, despite...
The readiness of local NHS and social care services to treat patients with long-term conditions (including multiple conditions) within the community

10. Most patients with continence problems are already treated in the community for the majority of their care. However, there are a number of practical steps which could be taken to improve the quality of service provided within the community and ensure better outcomes for patients.

11. Commissioners could be encouraged to think holistically about the impact of their spending decisions on the overall health budget, rather than just on specific areas, and avoid “silo budgeting”. Often the goal of staff making decisions about the range of available urology products seems to be to direct patients to cheaper products and so save money—however, as we have highlighted above, directing patients towards unsuitable products can have consequences with significant financial implications—including increased waste of products, increased tendency towards infection, and a lower ability to maintain a social and working life. This can impact on the welfare budget as well as the NHS budget.

12. Staff involved in making decisions about which products patients should use—from procurement staff to GPs to community nurses—could benefit from increased training on the kinds of products which they use, to improve their knowledge of how their decisions can impact on patient outcomes as well as budgets.

13. Patients should also be given better access to specialist services or nurses, so that they can get better advice on which products will help them to meet their needs, from a healthcare professional who has a good knowledge of both the system and the products available.

14. There also needs to be consideration of how care in the community and the hospital interact with each other. For example, if patients learn how to use a particular product within the acute setting, and then this is not included on the local formulary, then this can prevent a smooth transition to the community setting and prevent the patient from developing a regime to manage their condition.

15. Equally, given that many patients with long-term conditions have frequent spells in hospital, there needs to be greater consideration of how care between the community and the hospital is joined up. This means, for example, ensuring that patients in hospital are able to access the products which they would normally be able to get in the community.

16. As we have noted above, proper community care can reduce the need for hospital admissions, particularly emergencies. The Health Secretary recently raised the issue that primary care needs to look after patients in the community and ensure they don’t become ill, rather than “simply acting as a gateway” to hospital. If patients are not able to access specialist continence advice or are given unsuitable products, this can increase the levels of ill-health and the need for admission to hospital.

The practical assistance offered to commissioners to support the design of services which promote community-based care and provide for the integration of health and social care in the management of long-term conditions

17. There are a number of forms of practical assistance which could be improved to support better continence care within the community.

18. As noted above, it would be helpful if staff, both on the procurement side and the clinical side, were offered better training on the Drug Tariff, the products available, and how to help patients choose the most appropriate products.

19. It would also be helpful if there was better provision of information, both to patients and to staff, on how the Drug Tariff works and the products which are available. While GPs and nurses deal with a wide range of patients and conditions and should not be expected to know every detail about continence, they should know where they can turn to for information or point their patients to—including sources such as the internet, magazines produced by charities, and suppliers of the products.

20. In addition to this, there is also a need to consider how patients and clinicians are informed about new innovative products for bladder and bowel management. Innovation in urology and continence care has proved vital in improving the quality of patient care, with products designed for easy use by patient users in lifestyle situations at and away from home rather than by healthcare professionals in a clinical setting. However, if neither patients nor clinicians know about such products, then they will not be able to reach their potential.
The ability of NHS and social care providers to treat multi-morbidities and the patient as a person rather than focusing on individual conditions

21. To ensure that patients are treated as a person, with their condition or conditions considered as a whole, there is a need to improve the amount of consideration given to continence care.

22. For example, if patients have conditions which may include continence problems as an element, their GP or nurse should actively ask about their condition and whether they are experiencing any problems with continence. This is an issue which patients (and sometimes GPs) are often reluctant to discuss due to embarrassment, and there needs to be a greater focus on ensuring that these issues are actively raised, and that patients are referred to specialist service such as continence advice services where necessary.

23. As we have noted above, GPs and nurses also need to ensure that they are considering the individual needs and preferences of their patients, so that they can find the best solution for their needs.

The extent to which patients are being offered personalised services (including evidence of their contribution to better outcomes)

24. Anecdotally, we know that patients who could benefit from being referred to a continence adviser for specialist advice and support are not always given this opportunity. As mentioned above, it would be beneficial for GPs and nurses to more proactively ask about continence problems, particularly patients with long-term conditions which tend to see a higher incidence of such problems.

25. Commissioners should also be encouraged to ensure that they provide services with tailored support for individual patients. For example, we are aware of one PCT where concerns had been raised about the quality of the continence service. A new service was designed with a centralised approach, with financial and clinical responsibility residing with the specialist continence nurses running the service, rather than individual GPs who may not have the required knowledge to effectively prescribe products.

26. This has reduced product wastage, often caused by inappropriate use of products or by patients receiving far more product than is actually necessary, which arose in part because nobody was properly reviewing patients’ prescriptions. The model successfully addresses issues of oversupply and prescription of unsuitable products through face to face contact with specialist continence nurses running the service, ensuring more effective use of NHS money and resources, as well as improved clinical outcomes for patients.

27. Rather than contacting their GPs, patients now contact the continence service directly to request prescriptions for continence products, with clinical reviews a core element of the new service. Every time a prescription is ordered, a telephone triage is carried out, with the prescription coordinator asking questions about issues such as UTIs, skin soreness, and product performance and faults. If problems are identified, then patients are referred to the continence nurse specialist, to ensure a clinical review is undertaken before further products are issued.

28. If no problems are identified, then a prescription is issued. Patients have a choice of receiving the prescription themselves to take to the dispenser of their choice, having the prescription sent to the chemist of their choice, or having the prescription sent to a DAC.

29. Within this service, the Drug Tariff is respected; the continence service is able to prescribe any product listed on the national framework.

30. The Trust identified that introducing the new service has allowed it to make significant cost savings of around 10%, which have been reinvested back in the service. It is clear that there are many positive features to this service, and good patient feedback has also been received, demonstrating that it is possible to save money while providing a more personalised service which takes a proactive approach to addressing the specific needs of patients.

Conclusion and Recommendations

31. The UTA would make the following recommendations to improve the management of long-term conditions:

— Clinicians should be encouraged to consider the associated problems, such as urinary incontinence, which may arise from certain long-term conditions, and take proactive steps to assess their patients' wellbeing in this area.

— Clinicians should be encouraged to consider how decisions on how to treat one aspect of a long-term condition, such as incontinence, can impact on the overall wellbeing of patients and their ability to live independently and remain in employment.

— The Department of Health should be encouraged to ensure that choice of treatment options, such as urology devices, it maintained for those with long-term conditions, and that national processes such as the Drug Tariff are respected.
— GPs and nurses should be offered increased training on how to assist patients with continence problems, including how to be proactive in identifying problems and how to increase knowledge of the available treatment and management options.

9 May 2013

Written evidence from the Multiple Sclerosis Trust (LTC 62)

INTRODUCTION
— The MS Trust is a national charity representing the interests of 100,000 people with MS in the UK. We provide information for anyone affected by MS, education for MS specialist nurses and therapists, and funding for research into managing the symptoms of MS.
— MS is the most common long-term neurological condition diagnosed in young adults of working age (20–40). There is no known cure although there are treatments for relapsing/remitting MS which can delay the onset of the progressive stage of the condition; these apply to around half of the MS population.
— MS is uncommon: prevalence in England is around 140 cases per 100,000 people.
— People with MS benefit most from ready access to MS specialist services. The key person in this relationship is the MS specialist nurse, who acts as a care co-ordinator, offering holistic symptom management, making appropriate referrals, and often negotiating the boundary between health and social care.
— Specialist MS care is only available patchily in community settings. Most MS specialist care is available in hospitals via the hub-and-spoke model, with the hub being a teaching hospital and the spoke a local District General Hospital.
— The hub-and-spoke model works well so long as people with MS are able and willing to travel. Experience indicates that older people with MS or people with progressive forms of MS become dependent on primary care.
— Two main problems result from dependency on primary care: poor management of MS symptoms resulting from a lack of understanding about the condition; and a tendency to attribute all symptoms to MS when they may indicate a comorbidity.
— The MS Trust’s preferred solution would be greater outreach of MS specialist nurses into community settings, where they could act as care co-ordinators.

The scope for varying the current mix of service responsibilities so that more people are treated outside hospital and the consequences of such service re-design for costs and effectiveness

The readiness of local NHS and social care services to treat patients with long-term conditions (including multiple conditions) within the community

1. We wish to consider both these questions together.

2. People with multiple sclerosis depend on a combination of health professionals and skills for competent management of their condition. Very often, the single most important health professional is the MS specialist nurse, who can advise on a range of symptom management.

3. Multiple sclerosis is a fluctuating condition but at some point most people with MS will enter a stage where they become progressively more disabled, with both physical and cognitive symptoms.

4. The majority of MS specialist nurses are employed by neuroscience services based in teaching hospitals. Only some have a community outreach role.

5. People with MS need significant intervention from specialist health professionals at times of major change in their condition, such as around diagnosis, around pregnancy (for women), and around the time someone with relapsing/remitting disease enters the progressive phase of the condition.

6. Anecdotal evidence from people with MS and from hospital-based MS specialist nurses and neurologists indicates that many people with MS reach a stage where they stop attending hospital for clinic appointments. Travel becomes too significant a barrier.

7. At this point, they depend on their GP and community nurses, who do not have the specialist skills and expertise to deliver MS-specific care. In these settings, we often hear of people with symptoms that are not well managed, and experiencing symptoms that are attributed to their MS, when there may be other causes which are not properly investigated. This leads to a risk of unnecessary hospital admission.

8. Based on caseload alone, employing MS specialist nurses only in hospitals is more financially attractive. A typical hospital-based MS specialist nurse may have a caseload of 700 patients, while community-based MS specialist nurses may have a caseload of as few as 150 patients. In a hospital setting, the majority of patients will come back for an annual review. Patients based in the community are more likely to have complex
disability and be more expensive to the NHS. Here the specialist nurse will engage in more complex case management, symptom management and care co-ordination.


10. Access to some services is still extremely poor. It’s difficult to be sure whether this is wholly due to a lack of provision or to inadequate referrals. Still, in a 2011 audit of MS services, only 43% of people with MS reported access to neurorehabilitation, most reported no access to specialist vocational rehabilitation and only 44% of people with MS had been given all the mobility equipment they were assessed as needing [Royal College of Physician & Multiple Sclerosis Trust. The national audit of services for people with multiple sclerosis. RCP & MS Trust: London & Letchworth; 2011. http://www.mstrust.org.uk/research/mstrustprojects/projects/rcp2011–2.jsp].

11. Mobility equipment, such as frames, walkers, sticks and wheelchairs, grab rails and stairlifts may be provided by the NHS or by social services, depending on the type of equipment needed and the environment in which it’s provided. The poor provision found by the Audit suggests that at the very least, social care and health are not integrating well.

The ability of NHS and social care providers to treat multi-morbidities and the patient as a person rather than focusing on individual conditions

The interaction between mental health conditions and long-term physical health conditions

12. We have taken these two questions together as many of the comorbidities in MS relate to mental ill-health rather than physical comorbidities.

13. A host of symptoms develop as a result of having MS. Not everyone with MS will develop all these symptoms, but they include: fatigue, sleep disorders, spasticity, tremor, balance problems and ataxia, neuropathic pain, urinary and faecal incontinence, loss of mobility, visual problems, speech and swallowing disorders; also mental health symptoms, such as anxiety and depression, and sometimes more severe mental health disorders.

14. All these symptoms are treatable but there is a tendency for GPs and community health professionals to attribute any symptoms someone with MS experiences to their MS, rather than to investigate. For example, faecal incontinence, a known symptom of MS, is rarely investigated. Therefore, possible other causes such as an underlying bowel condition or drug side effects are not considered.

15. MS does not protect an individual against developing another long-term condition, such as diabetes or asthma or cancer or heart disease etc; conversely, someone with a pre-existing long term condition may develop MS.

16. There has been little research into managing comorbidities in MS, so we are dependent on individual case histories and experience. Our experience suggests that care is far from joined up for individuals with comorbid long-term conditions. For example, one of our supporters has MS and has been profoundly deaf since birth; her audiologist is based at one hospital while her neurologist is based at another hospital in a different city some thirty miles distant. Both consultants attribute the problems she experiences with balance to the other condition. Neither consultant communicates well or in a timely fashion with the other.

17. We have heard similar stories from the families of people with MS who have developed significant mental health symptoms. Occasionally in MS, cognitive symptoms can degenerate into florid psychosis or dementia, or both. We have experienced more than one case where an individual with MS has been admitted to inpatient psychiatric care but the acute mental health unit has not been able to deal with the patient’s physical needs. The individuals involved were wheelchair users, with complex disability.

18. One noted high risk among people with MS is a greater risk of bone fracture caused by falls, caused themselves by poor balance and coordination, plus a greater risk of osteopenia/osteoporosis that results from lack of weight-bearing mobility, particularly in wheelchair users. Treatment of the bone fracture is normally good but our supporters report very little access to preventive care, such as falls prevention programmes, or bone density scanning and follow-up treatment.

19. The commonest comorbidities in MS are depression and anxiety. Primary care treatment is normally successful. However, in practice it depends on the GP whether an individual is managed in primary care or whether they are referred back to a neurologist, with attendant waiting times.

The implications of an ageing population for the prevalence and type of long term conditions, together with evidence about the extent to which existing services will have the capacity to meet future demand

20. Epidemiological studies for the incidence and prevalence of MS in the UK are sparse, and there is no official MS register, but in recent years, localised research indicates that incidence and prevalence of MS is
21. A large number of people with MS are diagnosed with relapsing/remitting forms, which can be treated with disease modifying therapy. The aim of disease modifying therapy is to delay the transition to a progressive form of the condition, so to enable individuals to live fully able lives for as long as possible. However, even with current therapies, many people with MS will start to develop significant disability in around 15–20 years from diagnosis. [Tedeholm H, et al. Time to secondary progression in patients with multiple sclerosis who were treated with first generation immunomodulating drugs. Multiple Sclerosis 2012; Nov 1. Epub ahead of print]

22. Average age at diagnosis is at about 30 years of age. Around 10% of people will be diagnosed with a progressive condition from onset.

23. MS reduces life expectancy only slightly, by around five years from the average. The effect of disease modifying drug therapy on average life expectancy is not yet known.

24. Given points 20–23 above, we anticipate that the total MS population will continue to grow, partly because incidence is rising, and partly as people live longer with the condition. Our expectation is that people with MS will, like the rest of the UK population, continue to live longer. However, many people with MS will grow old with significant disability and their greater life expectancy may involve living with complex physical and cognitive symptoms.

25. Like the rest of the population, the indications are that older people with MS are likely to develop more comorbid conditions, eg arthritis, Type 2 diabetes. Very little systematic research in this area makes it difficult to specify which conditions are most common.

26. At the moment, there is very little evidence that the health and social care system has enough capacity to cope with this increased pressure. The UK has fewer neurologists per head of population than any other country in Europe, of around 1 neurologist per 140,000 population; this compares adversely to Europe and North America where there is an average of 1 neurologist to 40,000 population [Royal College of Physicians and Association of British Neurologists. Local adult neurology services for the next decade. London: RCP 2011. http://bookshop.rcplondon.ac.uk/details.aspx?e=354]

27. Currently there are around 235 whole-time equivalent MS specialist nurses in post. It is clear that some areas are very well served for MS nurses whereas others have very poor coverage. [MS Trust. Defining the value of MS specialist nurses. Letchworth: MS Trust; 2012 http://www.mstrust.org.uk/research/mstrustprojects/projects/defining-the-value-of-ms-specialist-nurses-detailed-summary-3.jsp].

28. In the past 10 years, neurology has been granted a great deal more funding but this has not translated into significant improvements in care [House of Commons Public Accounts Committee: Seventy-second report. Services for people with neurological conditions. 2012: http://www.parliament.uk/business/committees/committees-a-z/commons-select/public-accounts-committee/news/neuro-report/]. We would suggest that this is taken into consideration when recommendations are made for improving services.

29. Adequate social care is a major problem for less able people with MS. As increasing pressures on the system mean that social care is provided only to individuals with significant care needs, there is a very high risk that people with MS who need small amounts of help will develop unnecessary symptoms or fall, thus requiring acute admissions for fracture.

30. To combat these issues, the MS Trust would like to see greater funding for social care and for equipment services, and far more specialised care delivered in the community, by increased outreach from MS specialist nurses and therapists into community settings, and joint assessments with GPs, community nurses and social workers. We believe that this would significant improve holistic preventive care for individuals with MS, especially as their life expectancy increases.

9 May 2013

Written evidence from the Optical Confederation (LTC 63)

SUMMARY

The Optical Confederation welcomes the opportunity to contribute to the Health Select Committee’s inquiry on the way in which the NHS and social care system in England supports people with long-term conditions.

Community optometrists and opticians, through sight testing, case finding and vision correction of people with long term conditions, play an essential role in the new NHS and social care system. They often interact, either in an optical practice or through the domiciliary eye care service, with people who have long term...
conditions, such as dementia, learning disabilities,410 autism, macular degeneration, diabetes or who are in stroke rehabilitation.411 Prevention of sight loss for people with these conditions can help them maintain independent lives as far as possible and reduce the need for social care support, which would be necessary if sight were lost permanently.

These community services go above and beyond the sight testing service, yet are not always recognised in this way by commissioners. There is a real opportunity under the current NHS reforms for such services to be recognised as part of an integrated health and social care system.

The Committee is interested in the impact of an ageing population on the health and social care system. Although all age groups can be affected by visual impairment, the main causes of sight loss in the UK have a higher incidence among the over 65s. One in five people aged 75 and one in two aged 90 and over are living with sight loss. Yet, around half of all sight loss is thought to be preventable, rising to up to 70% amongst the elderly.412

Given these figures, a corresponding increase in demand for NHS eye care services is likely to follow and careful planning will be required by all health and social care professionals in order to slow, or even to halt, this expected rise. The severity of this future challenge is detailed below. The Government has recognised this issue in two important ways:

— the inclusion of a preventable sight loss indicator in its public health outcomes framework;413
—and

— the establishment of Local Eye Health Networks (LEHNs) across all NHS England Local Areas.

1. LOCAL EYE HEALTH NETWORKS

1.1 The aim is that Local Eye Health Networks (LEHNs) will bring together all local eye health stakeholders in a clinically-led, patient- and population-focused model to achieve progress against the sight loss indicator locally. This will involve assessing local eye health needs, redesigning pathways as necessary in line with QIPP414 principles and maximising the deployment of resources across primary, secondary, social and voluntary sector care for health gain.

2. IT

2.1 A key factor in the success of this approach will be the interconnectivity of community optical, GP, Choose and Book and hospital eye service IT systems to enable rapid exchange of clinical, referral, financial and audit data. The Scottish Government is already making good progress towards this goal and, as a Confederation, we warmly welcomed NHS England’s announcement in June 2012 that they were in the early stages of developing a national specification for primary ophthalmic services (POS) claims and payments, an important first step towards greater connectivity in England and collecting outcomes data. We look forward to working with all relevant stakeholders to achieve integrated IT systems, as mentioned above, as their absence is a major obstacle to integrated eye care.

3. DIABETES

3.1 The Committee expressed a wish to review in particular services provided for patients with diabetes, as part of this inquiry. Some of the key symptoms that lead to an investigation for diabetes are visual (eg blurred vision, variable vision). Most sight loss due to diabetes can be prevented, provided it is diagnosed early and treated promptly. For example, diabetic retinopathy is the leading cause of preventable sight loss in working age people in the UK and early detection through screening halves the risk of blindness. All people with a family history or suspected diabetes should also be encouraged to have regular sight tests to pick up any pathology.

3.2 We support the recommendations made by the All Party Parliamentary Group on Diabetes which calls for retinal screening to be carried out, at least once a year, as part of a person with diabetes’ annual review.415

410 People with learning disabilities are ten times more likely to have eye problems, but are less likely to receive timely and appropriate care than the rest of the population. Recognising the need to improve access to good eye care services, the new Community Eye Care Pathway for Adults and Young People with Learning Disabilities has been developed by the Local Optical Committee Support Unit (LOC SU). This pathway has been developed in conjunction with two leading charities, Mencap and the SeeAbility, to ensure it reflects the needs of people with learning disabilities and is based on established, successful, learning disability services provided by community optometrists in a number of areas in England. More details can be found via the following link: http://www.locsu.co.uk/enhanced-services-pathways/community-eye-care-pathway-for-adults-and-young-pe (Last accessed April 2013)

411 A recent survey conducted by LOC SU has shown that more than 85% of practitioners routinely examine stroke patients within their practice and more than 70% would want to participate in any future enhanced eye care service pathway. Further details can be provided, upon request.

412 Tate, et al (2005). The prevalence of visual impairment in the UK; A review of the literature

413 Improving outcomes and supporting transparency—Part 2: Summary technical specifications of public health indicators, Jan 2012, Department of Health, Indicator 4.12, p.77–78

414 Quality, Innovation, Productivity and Prevention (QIPP)

These programmes must track patients’ progress to ensure they receive annual screening and access to prompt treatment and follow-up when needed. Screening services must also have good links with local provider eye departments and Local Eye Health Networks—see above. We welcome the Government’s inclusion of non-cancer screening programmes including the national diabetic retinopathy screening programme in its Public Health Outcomes Framework and look forward to working with all relevant stakeholders on the data.  

4. About Us

4.1 The Optical Confederation represents the 12,000 optometrists, the 6,000 dispensing opticians and 7,000 optical businesses in the UK who provide high-quality and accessible eye care services to the whole population. The Confederation is a coalition of the five optical representative bodies: the Association of British Dispensing Opticians (ABDO); the Association of Contact Lens Manufacturers (ACLM); the Association of Optometrists (AOP); the Federation of Manufacturing Opticians (FMO) and the Federation of Opticians (FODO). As a Confederation, we work with others to improve eye health for the public good.

9 May 2013

Written evidence from Coloplast (LTC 64)

Summary

— Coloplast is a leading medical technology company specialising in intimate healthcare needs. Coloplast develops products and services to make life easier for people with very personal medical conditions, including urology and continence care, ostomy care and wound care.

— Continence and ostomy care are an important factor in a wide variety of long-term conditions, such as neurological diseases, spinal injuries and cancer. We supply our products into the NHS, both into secondary care and into tertiary care through Part IX of the Drug Tariff.

— Access to appropriate products and specialist continence advice is very important for patients with long-term conditions; it helps reduce ill health, improve outcomes, and allows more independent living. However, patients often experience difficulties accessing specialist advice and/or the most appropriate products for their needs.

— Both clinical staff and procurement staff need to consider the overall impact of decisions made about continence management, including in terms of patient outcomes, amount of care required, and the overall cost to the health service.

— There is also a need to ensure proper coordination between treatment in primary care and treatment in hospitals, particularly for patients who may move between the two.

Introduction

1. Coloplast is a leading medical technology company specialising in intimate healthcare needs. Coloplast develops products and services to make life easier for people with very personal medical conditions, including urology and continence care, ostomy care and wound care. These products are used by people with a wide variety of long-term conditions, such as those with neurological diseases, spinal injuries and cancer. We supply our products into the NHS, both into secondary care and into primary care through Part IX of the Drug Tariff.

2. Currently, urology and stoma products are supplied to patients in primary care via Part IX of the Drug Tariff, which lists the urology and stoma products that have been approved by the Secretary of State for Health for prescription on the NHS and the price which should be paid for each product. All products listed on the Drug Tariff are considered to be clinically effective and cost effective at a national level. This offers a number of benefits, including the protection of patient choice, the avoidance of a postcode lottery and price certainty for the NHS.

3. Products are prescribed to patients by GPs and nurses, but often there are local measures, put in place by procurement officials, which aim to restrict the choice available to prescribers and patients—these include restrictive formularies, tenders and the use of preferred providers.

4. Having access to the right products can help patients to manage long-term conditions more independently, to reduce their incidence of urinary tract infections and to maintain a work and social life. Therefore, while directing patients towards cheaper products may lead to small, short term savings, it can lead to wider spending elsewhere in the health and social care system. This response explores how continence and stoma care are managed as part of long-term conditions.

HOW DOES CONTINENCE IMPACT ON LONG-TERM CONDITIONS?

5. Continence problems form a part of many complex long-term conditions. This could include neurological conditions such as Parkinson’s disease and MS, cancer, stroke and spinal injuries. Many of these patients will require support with their continence needs for long-periods of time—for the rest of their lives in a lot of cases.

[Improving outcomes and supporting transparency—Part 2: Summary technical specifications of public health indicators, Jan 2012, Department of Health, Indicator 2.21, page 46]
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However, continence care does not always receive significant attention as part of a strategy to manage long-term conditions, and more needs to be done to increase the focus in this area and ensure that patients are getting the support which they need.

6. The Royal College of Physicians previously identified in their National Audit of Continence Care, published in 2010, that there was a lack of consistency between NHS trusts in terms of the type, quality and quantity of continence supplies available to patients, as well as identifying other concerns about the quality of service provided.

7. One particular concern which is frequently raised in relation to continence and stoma care is that patients cannot always access the products which they need to ensure that their needs are met. This could mean being able to access a particular type of catheter which offers the discretion they need, being able to access leg bags which are suitable for those with a lack of manual dexterity, or being able to access bowel management products such as our innovative anal irrigation system, Peristeen, when more conservative methods have failed to offer them the freedom, comfort, and sense of security which they need. The differences between products are not always obvious to those who do not use the products or have specialist training, but directing patients towards the wrong products or trying to limit access to new innovation can have very real consequences across a number of areas, such as increased wastage of inappropriate products, increased urinary tract infections from having to use less suitable products or increased reliance on carers or reduced ability to remain in employment.

8. For example, for a patient with MS who is suffering from chronic constipation, if methods such as enemas, laxatives, and suppositories have not worked, they may be required to use manual evacuation. As well as the obvious concerns which this raises about patient dignity, it also creates significant costs in terms of nursing care and leaves the patient much less able to leave the house and participate in work and social life. Despite evidence showing that Peristeen can lead to significant improvements in patient outcomes as well as saving money compared to conservative bowel management methods, it is not universally available across the NHS.

9. The reasons for the lack of consistent good quality continence care include a lack of knowledge among non-specialist healthcare professionals, which means that they are unable to recommend the best treatment for patients, a lack of willingness to directly address these issues with patients and refer them on to specialist continence nurses, and the use of formularies and other methods designed to limit the choice of urology product available and direct patients towards cheaper products.

The readiness of local NHS and social care services to treat patients with long-term conditions (including multiple conditions) within the community

10. Given the large number of patients who have their continence problems dealt with, alongside other conditions, in the community, it is essential that good quality care is available within this setting.

11. Effective management of continence needs in patients with long-term conditions impacts their quality of life and can help reduce repeated hospital admissions through reducing problems such as urinary tract infections.

12. However, many patients with long-term conditions will need to be admitted to hospital for other reasons as part of their care, and it is vital that there is coordination between primary and secondary care so that patients are able to access all the devices and other treatments in hospital which they use during their normal day-to-day life.

13. As alluded to above, one problem which is often experienced is the tendency for those in charge of commissioning care to think about issues in isolation, rather than as a whole. This can lead to, for example, the introduction of formularies which aim to reduce the amount of money spent on stoma and urology products—while not taking into account the increased costs which could result if this leads to worse outcomes for patients or less effective management of long-term conditions.

14. Therefore, we would recommend that there needs to be incentives for staff within Clinical Commissioning Groups and other NHS organisations to make a more holistic assessment of the impact of their decisions.

15. Staff, both on the clinical and procurement side, could also benefit from further training which aims to increase knowledge of how many long-term conditions impact on continence care. GPs and nurses should be actively encouraged to ask patients with long-term conditions if they are having any problems with either urinary incontinence or bowel management, rather than waiting for patients to raise these issues.

16. There should also be a fresh look at the patient pathway to see if the route to specialist continence advice for those patients who do need it could be made simpler, if the NICE guidance in this area is still fit for purpose or needs updating.
The practical assistance offered to commissioners to support the design of services which promote community-based care and provide for the integration of health and social care in the management of long-term conditions

17. In addition to training, better provision of information could help to ensure that commissioners are able to design services which are fit for purpose and ensure that those with continence patients are able to access necessary advice.

18. This could include information for GPs and nurses who are not specialists in this area on the kinds of conditions which feature continence problems, to encourage them to ask more proactive questions. It could also include increasing knowledge of where clinicians can point patients for more specialist information, such as magazines, websites and suppliers.

19. As we have noted above, innovation is very important in improve the quality of continence care offered to patients, and healthcare professionals need to be kept up to date with new products on the market. We are aware of examples where study days have been organised to increase knowledge of the urology or stoma products available, but only products or companies included on the local formulary are included. This is a particular problem where formularies are only updated every two years or more, meaning a long-period where knowledge of new innovations remains low.

The ability of NHS and social care providers to treat multi-morbidities and the patient as a person rather than focusing on individual conditions

20. To ensure that patients are treated as a person, with their condition or conditions considered as a whole, there is a need to improve the amount of consideration given to continence care.

21. For example, if patients have conditions which may include continence problems as an element, their GP or nurse should actively ask about their condition and whether they are experiencing any problems with continence. This is an issue which patients (and sometimes GPs) are often reluctant to discuss due to embarrassment, and there needs to be a greater focus on ensuring that these issues are actively raised, and that patients are referred to specialist service such as continence advice services where necessary.

22. As we have noted above, GPs and nurses also need to ensure that they are considering the individual needs and preferences of their patients, so that they can find the best solution for their needs.

The extent to which patients are being offered personalised services (including evidence of their contribution to better outcomes)

23. One factor which would contribute to more personalised service for patients would be if more patients were able to access a continence adviser to received specialist, tailored advice on how they can deal with particular problems—including which devices might be best utilised to manage their conditions.

24. As we have noted above, many GPs and nurses do not take the initiative to ask about bowel or continence problems and should be incentivised to do so, particular with those suffering from long-term conditions such as spinal injuries, MS, or Parkinson’s disease where continence is a common factor. This would lead to more patients being given appropriate advice or referred to a continence service where appropriate.

25. Patients should also be made more aware of the fact that they have the ability to self-refer to a continence service if they do not wish to go through their GP.

26. Conclusion and recommendations

- GPs and other healthcare professionals should be incentivised to be proactive in managing continence problems in those with long-term conditions, such as through the Quality and Outcomes Framework.
- The referral pathways for patients to continence services should be reviewed to ensure that they are simple and effective, and allow patients to access the advice which they need.
- Patients should be made more aware of the fact that they are able to self-refer to a continence service if they could prefer not to go through their GP.
- Healthcare professionals should be encouraged to stay informed about the latest innovations in medical devices so that patients are able to access products which can improve clinical outcomes and their quality of life.
- Commissioners should ensure that they consider the wider implications of decisions they make about access to particular products, rather than aiming to make short-term savings.

May 2013
Written evidence from The Society of Homeopaths (LTC 65)

1. SUMMARY

The Society of Homeopaths (hereafter “the Society”) is composed of approximately 1,300 practicing homeopaths and represents the majority of professional homeopaths practicing in the UK. There is a significant trend for homeopaths working privately and in NHS settings to see many patients suffering from long-term conditions that have failed to respond to conventional medicine. This document will therefore outline:

— How homeopathic treatment is well placed to support patients with long-term conditions.
— Evidence that homeopathy is valued by the patients who seek it out.
— Evidence of clinical effectiveness in specific long-term conditions.
— Evidence supporting the cost-effectiveness of homeopathic treatment.

This document will also highlight the potential for homeopathy as a medical system, treatment option and philosophy to address the following issues of interest to the Health Committee:

— Treating multi-morbidities by emphasising the patient as a person rather than focusing on individual conditions.
— The interaction between mental health and physical health conditions.
— The extent to which patients are being offered personalised services (including evidence of their contribution to better outcomes).
— Current examples of effective integration of services which treat and manage long-term conditions.

2. THE HOMEOPATHIC APPROACH

Homeopaths often see patients after they have received a medical diagnosis from their doctor and many of these patients have long-term health problems that fail to respond to conventional medicine. Some individuals seek a homeopath because they are experiencing side effects from conventional drugs and others because conventional tests have failed to find the cause of their problem. As a system of medicine, homeopathy aims to treat patients as whole people, rather than focusing on a course of action for each disease diagnosis, thus offering a different approach. As such, homeopathic treatment can be considered as a supportive option in almost any condition where tissue has not been irrevocably damaged. Homeopaths working according to the Society’s code of ethics encourage their patients to keep their appropriate medical practitioners informed when they seek homeopathic treatment and as treatment progresses. When necessary homeopathic and conventional approaches can be used alongside one another to give the most appropriate care to each individual patient, thus integrating all medical approaches and adjunctive advice the patient has been given to manage their health.

3. WHAT IS HOMEOPATHY?

The MeSH definition of homeopathy is:

“A system of therapeutics founded by Samuel Hahnemann (1755–1843), based on the Law of Similars where ‘like cures like’. Diseases are treated by highly diluted substances that cause, in healthy persons, symptoms like those to be treated. The dilutions are repeated so many times that there is less than one molecule per dose and it is suggested that benefit is from the energetic life force of the original substance”.

Homeopathy can therefore be seen as a “holistic” therapy, such that homeopathic care takes into account all aspects of the patient as an individual assessing their symptoms on mental, emotional, physical and general levels.

During a consultation the professional homeopath will focus on building up a complete picture of an individual's unique make up considering all aspects of the patient’s health including diet, medical history, life events, lifestyle and personality. Homeopathic prescriptions are based on the process of matching this unique collection of symptoms as closely as possible with those of an appropriate homeopathic medicine (called a “remedy”), rather than automatically prescribing the same medicine for a named condition. This approach to understanding patients’ cases makes homeopathy well placed to treat those people with a diversity of complaints that would conventionally be given a different medication for each condition. For example, a person with asthma, allergies and constipation would typically require three different medications, but would be most likely to require only one homeopathic remedy that covers the totality of their case.

4. HOMEOPATHIC PHILOSOPHY

The philosophy that underpins the homeopathic medical system considers that physical ill health (in the absence of inherited disorders, accidents or physical trauma) can reflect unresolved life events, leading to prolonged underlying emotional stress. The professional homeopath will always ask a patient what was
happening in their lives when the symptoms started or worsened. In this way, homeopathic philosophy places an equal importance on both emotional and physical wellbeing.

For example, a patient who developed hypertension following a significant grief would receive a homeopathic remedy that aimed to support resolution of this grief to first reduce emotional stress, then reducing physiological stress and ultimately reducing the hypertension. This would be done alongside conventional medical care and any other adjunctive treatment required, ensuring that each patient is appropriately supported on all fronts. Patients’ experience of successful homeopathic treatment is often that they first feel better “in themselves” and then that their physical symptoms start to improve, or become more manageable.

5. THE THERAPEUTIC ENCOUNTER

Patients often find the experience of telling their unique story to a sympathetic and supportive professional to be therapeutic (Eyles et al., 2012). There is some evidence to suggest that this aspect of the encounter with a professional homeopath may explain homeopathy’s therapeutic effectiveness (Jacobs et al., 2005; Brien et al., 2010). Indeed, this can be considered as the most parsimonious explanation for patient responses to homeopathic treatment while we lack a definitive explanation for the mechanism of action of homeopathic remedies. However, there is also evidence of the effectiveness of homeopathic remedies in the absence of the consultation (Frei et al., 2005) suggesting that patient benefit cannot simply be reduced to a therapeutic encounter.

6. WHY PATIENTS ChOOSE HOMEOPATHY: QUALITATIVE EVIDENCE FROM UK STUDIES

A pre-audit study exploring the motivation for patients to attend the Bristol Homeopathic Hospital for homeopathic treatment found that patient’s emphasised “treating the whole person” and a “desire to look at illness in a more complex way” (Thompson et al., 2007). Additionally, a qualitative study of patients choosing complementary therapies for asthma (Shaw et al., 2006) found that it “empowered them to take greater personal control over their condition rather than feel dependant on medication” and “enabled exploration of a broader range of possible causes of their asthma than commonly discussed within NHS settings”. Homeopathy offers an approach to understanding illness that patients with long-term conditions appreciate and appear to be paying for in the absence of access to NHS provision (Perry, 2013). A 2013 audit of 100 randomly selected patients at a privately run integrated medicine clinic (www.wellforce.co.uk) found that many patients with chronic fatigue syndrome, fibromyalgia, arthritis and multiple sclerosis were attending: pain, fatigue, anxiety and depression represented their most common symptoms. A survey by Thomas et al. (2003), also found that 90% of complementary and alternative medicine (CAM) provision is purchased privately with total expenditure estimated at £450 million for 1998, with 10% of the adult population contacting a CAM practitioner that year.

In addition to the clear demand for CAM healthcare in supporting patients with long-term conditions, a study carried out at the University of Sheffield on behalf of the Department of Health explored patient satisfaction with complementary therapies in the NHS and found them to be “overwhelmingly positive” (Luff and Thomas, 2000). Specific aspects valued by patients included the development of a therapeutic relationship with their practitioner, the caring nature of the practitioner, being involved in the process of care and a significant improvement in the quality of their lives.

7. WHERE PATIENTS ACCESS HOMEOPATHIC TREATMENT

Patients currently access homeopathic treatment from a variety of sources within the NHS including:

— three homeopathic hospitals in the UK (London, Bristol, Glasgow) and one ex hospital now NHS homeopathy clinic (Liverpool);
— some GP surgeries, where homeopathy is offered either by GPs also trained in homeopathy or by practice-funded homeopaths (eg Marylebone Health Centre);
— as an integrated component of palliative care (eg St Luke’s Hospice, Plymouth);
— as a specialist service for hard to treat conditions (eg within the rheumatology department at Barnsley hospital);
— as a specialist NHS clinic (eg Sheffield’s National Health Service community menopause clinic); and
— as a general NHS clinic (eg Manor clinic, Sheffield).

However, the majority of patients in the UK access homeopathic treatment privately. Less than 10% of GPs report using homeopathy (Perry et al., 2013) and homeopathic prescribing in the NHS appears to have fallen sharply between 2000 and 2010 (Beckford, 2011).

8. HOW PATIENTS WITH CHRONIC CONDITIONS FARE USING HOMEOPATHY

An observational study at the Bristol Homeopathic Hospital monitored treatment of >6,500 patients with chronic disease during a six year period (Spence et al., 2005). The aims of homeopathic treatment were to enhance general health and well-being, to improve symptom control and to reduce the impact of exacerbations
in patients’ chronic conditions: just over 50% of patients self-rated their health as “better” or “much better” and over 70% expressed a degree of improvement. These results concur with studies from other homeopathic hospitals: in Tunbridge Wells improvement was seen in 74% of 1372 patients (Clover, 2000); and in Liverpool improvement was seen in 76.6% of 1100 patients (Richardson, 2001).

An eight year longitudinal cohort study of over 3,500 adults and children (97% of whom were diagnosed with a chronic complaint) also found that patients receiving homeopathic treatment improved considerably (Witt, 2008). That is, 67% of adults and 80% of children achieved significant health improvements at two years after baseline, and this improvement was sustained for the following six years of the study.

9. How Children with Chronic Conditions Fare Using Homeopathy

Children with chronic conditions appear to respond particularly well to homeopathic treatment. In addition to the evidence above, 66% of children in the Bristol Homeopathic Hospital study described rating their health as “better” or “much better” and 80% stated a degree of improvement. 68% of the children with eczema reported that it was “better” or “much better” (Spence et al., 2005). Parents appear to be turning to homeopathic treatment for their children: 24% of children with chronic conditions in an outpatient setting in south-west England were found to be using some form of CAM, homeopathy being one of the most common (Simpson and Roman, 2001). The Avon longitudinal study found that children were using homeopathy for chronic conditions such as asthma, eczema, hay fever, epilepsy, and migraine (Thompson et al., 2010).

10. Evidence for Specific Chronic Conditions

It is fair to say that clinical trial evidence for the effectiveness of homeopathic treatment for specific conditions overall is sparse, although trials of homeopathy in chronic conditions such as fibromyalgia, rheumatoid arthritis, hypertension, eczema, asthma, depression, ADHD and chronic fatigue do exist. However, most trials done to date focus on assessing the efficacy of specific homeopathic remedies compared to placebo and these trials provide little useful information about the effectiveness of homeopathic treatment for patients in a real-world context. For example, two of four studies on homeopathic treatment of fibromyalgia focus on the efficacy of specific homeopathic remedies (Fisher, 1986; Fisher, 1989) while two other studies are closer to real-world homeopathic practice in allowing free choice of homeopathic remedies (Bell et al., 2004; Relton, 2009); interestingly, positive results were recorded in both trial types.

11. Adverse Effects

Homeopathy is generally considered to be a safe therapy, relatively free of adverse events when compared to the rate of side effects from conventional medications. The highly-diluted nature of homeopathic medicines means that they are unlikely to lead to toxicity-related adverse drug reactions (Kirby, 2002). Several studies have reviewed the evidence for homeopathic adverse events and together the conclusion is that as long as homeopathy is correctly administered by a professional, qualified, registered homeopath (such as those registered with the Society) it is safe (Bornhöft et al., 2006; Dantas and Rampes 2000; Endrizzi et al, 2005; Monk, 1986; Thompson et al, 2004).

12. Cost Effectiveness

Cost effectiveness studies indicate that the use of homeopathy as a treatment option can reduce financial burden on patients and healthcare providers alike.

In Europe, a Health Technology Assessment of homeopathy commissioned by the Swiss government recently concluded that homeopathy is “clinically effective, cost effective and safe” (Bornhöft et al, 2006). Additionally, a comparison of homeopathic and conventional treatment of 493 patients with chronic conditions in Germany found that homeopathy achieved better outcomes for similar costs (Witt et al, 2005) and a study involving 499 children with recurrent upper respiratory tract infections showed that homeopathic treatment was more clinically effective (fewer episodes of illness) and more cost-effective than antibiotics (Trichard et al., 2005).

Other studies in the UK suggest that homeopathy can save money by reducing the use of conventional drugs, both in a hospital and a GP setting. Specifically, a 500-patient survey at the Royal London Homeopathic Hospital showed that many patients were able to reduce or stop conventional medication following homeopathic treatment (Sharples et al, 2003) and a study examining prescription costs of 22 GPs in the UK found that practices which included a GP using homeopathy prescribed 12% fewer items of medication per patient (including both conventional drugs and homeopathic medicines) compared with other local practices (Swayne, 1992). Since long-term conditions often require long-term medication regimes, homeopathy has the potential to make a significantly positive impact on the NHS drug budget.

13. Summary

As described in this paper there is a compelling argument to be made that homeopathic treatment is a clinically and cost effective option to support patients with long-term conditions. Importantly, patients who receive homeopathic treatment are also overwhelmingly positive about the experience.
Offering homeopathic treatment to patients with long-term health conditions addresses many of the concerns described by the Health Committee as it:
— considers the patient as a whole person;
— treats individual people not their individual diagnoses;
— treats multi co-morbidities and offers a philosophical approach to support this;
— provides effective integrated care alongside other treatments;
— is appreciated by patients, who particularly value the personalised care they receive;
— is comparatively cost effective; and
— is available privately throughout the UK as well as part of the NHS in some areas.

The use of homeopathy in healthcare is increasing in other countries (eg India, Brazil and Japan) and from 1985 to 2001 CAM use in the UK also increased (Thomas and Coleman, 2003). However, UK support for homeopathy has recently seen an unfortunate decrease such that NHS-commissioned services, like the Sheffield menopause clinic and the Manor Clinic (http://www.shsc.nhs.uk) and the Liverpool hospital have been closed despite offering award winning services and fulfilling unmet needs. This may be due to NHS budget constraints; minimal education of doctors about CAM; and a decrease in GPs opinions about the effectiveness of homeopathy (48.7–21.9% in the last 10 years (Perry, 2013). A change in GP opinions may be a consequence of the unprecedented attempts by the biomedical community to discredit homeopathy in recent years (Anonymous, 2005; Bewley, 2011).

As outlined, homeopathy has an emerging evidence base of clinical effectiveness for specific named conditions, but it is important to appreciate that this remains in its infancy as most studies have focused on the efficacy of remedies in isolation: remedy efficacy is not relevant to patients with complex long-term health conditions, who need information about what homeopathy as a therapeutic intervention can do for them as individuals. As such, we would argue that there is a disconnection between patient perception and appreciation of homeopathy compared to medical, scientific and commissioner decision making. The NHS is currently not providing adequate homeopathic services that are clearly appreciated and needed by the public, especially those with long-term health conditions. We therefore suggest that the NHS could benefit from supporting the cheap homeopathic treatments already available at private homeopathy clinics across the country as well as commissioning specialist clinics to offer an integrated approach to health and wellbeing in order to benefit the long-term management of hard to treat chronic conditions.

9 May 2013

15. References


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Ev w148  Health Committee: Evidence


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Written evidence from The Work Foundation (LTC 68)

1. WHO WE ARE

1.1 The Work Foundation is the UK’s leading think tank specialising in labour markets and employment policy. We have a particular interest in how policy makers can help people with long term conditions remain in the labour market, and have recently published reports focusing on long term conditions such as schizophrenia, multiple sclerosis, cancer, inflammatory bowel disease, diabetes and musculoskeletal disorders (MSDs).

2. SUMMARY

2.1 Employment rates for people with long term health conditions are low, despite the fact that employment is both possible and beneficial for many people in this group.

2.2 As the population ages, and more people have long-term conditions and co-morbid conditions, this issue will become more pressing.

2.3 People with long term mental health conditions in particular are currently not receiving the support they need to enter, or remain in, the labour market.

2.4 Early, effective interventions have been demonstrated to lead to higher rates of recovery, particularly for people with a mental health condition.

2.5 Medical innovations should be explored, and a greater focus should be placed on the long term impacts of new technology, rather than short term cost. Wider savings, such as those made if a person is able to remain in employment, should be considered.

3. EMPLOYMENT CAN BE A BENEFICIAL OUTCOME FOR PEOPLE WITH A LONG TERM HEALTH CONDITION

3.1 Employment rates for people with long term conditions are low, with many people being unable to either find or maintain employment. In addition, many people with long-term conditions leave the labour market prematurely as a result of their condition, though often unavoidably. For example, people with MS leave work 18 years earlier than those without MS, while up to 40% of people with rheumatoid arthritis leave work within five years of diagnosis. This is a serious issue, which a comprehensive review of the management of long-term conditions must consider. Employment can have an important positive therapeutic and economic impact on the life of someone with a long term illness. For an individual, work can provide financial autonomy, self-respect, dignity, quality of life, and a sense of self-worth.\textsuperscript{419} Whilst it should be recognised that in some cases employment is not a viable or healthy option for an individual with a long term condition, and for some it may worsen their condition, this is not universal, and should not be considered the norm. For many people employment has been shown to have a positive impact in terms of health. For example, our recent research on schizophrenia highlighted that being in employment reduced the likelihood of relapse.

3.2 We believe that the NHS and the government need to do more to account for the importance of employment in the lives of people with long term conditions. Although employment is a measured outcome in the National Outcomes Framework, it is not part of the Clinical Commissioning Groups Outcome Indicator Set (CCG OIS). We recommend the Health Committee investigate the feasibility and appropriateness of changing this, and look at ways to encourage health care professionals to see employment as being within their remit as something that impacts on their patients. Ultimately, we have concluded that if work is not routinely regarded as an outcome of treatment then the incentives in the health system to promote job retention or return to work among people with long-term conditions will not be strong enough.

3.3 Employment can be a beneficial outcome for people with a long term health condition.

4. THE IMPACT OF AN AGEING POPULATION AND THE RISE OF CO-MORBIDITIES

4.1 As the population ages, and medical innovations lead to higher survival rates, more people of working age will have long term conditions. By 2030, approximately 21 million people of working age will have at least one long-term health condition—as much as half of the UK workforce.\textsuperscript{419} A rise in long-term conditions will result in a rise in co-morbidities—with people suffering from two or more conditions at the same time. It is common for people with a physical health condition to also suffer from some form of mental illness, and evidence suggests that there is an association between the two.\textsuperscript{420} With co-morbidity increasing healthcare costs by approximately 45%.\textsuperscript{421} There is also evidence to suggest that co-morbidities are synergistic, and can interact with each other to make both conditions worse.\textsuperscript{422}


\textsuperscript{420} Robin McGee and Katherine Ashby, “Exploring the connection between physical and mental health conditions” (The Work Foundation, 2010 http://www.theworkfoundation.com/assets/docs/publications/260_body_soul160910final.pdf)


\textsuperscript{422} Schmitz, N, Wang, J, Mall, A and Lesage, “A Joint effect of depression and chronic conditions on disability: Results from a population-based study” (Psychosomatic Medicine, 69, 332–338, 2007)
4.3 Mental health conditions are a particularly common form of co-morbidity. International studies have found that the rate of mental health problems is higher in people with chronic physical conditions.\textsuperscript{423} For example, people with diabetes are 50% more likely to have some form of mental illness. It should also be noted that there is some evidence to suggest the reverse can be true as well—with mental health conditions exacerbating or worsening physical health conditions. In other words, the physical health of someone with a co-morbid mental health condition is often worse than someone without.\textsuperscript{424}

5. MENTAL HEALTH AND SUPPORT IN THE COMMUNITY

5.1 The recent Schizophrenia Audit found that a third of service users in England and Wales were not offered any form of psychological therapy, despite the evidence of such interventions helping with management of symptoms generally, as well as employment outcomes. This is particularly the case with Cognitive Behavioural Therapy (CBT), which has been shown to help people with schizophrenia to return to work and retain employment. The Schizophrenia Commission found that only 1 in 10 people with schizophrenia who could benefit from CBT were receiving the treatment, while our own research found qualitative evidence which suggested that either this kind of support was simply not available or that health care professionals were inconsistent in prescribing it, feeling that employment was not “their area” or that whilst employment was a possibility for some patients, it would not be suitable for theirs.\textsuperscript{425} Making employment an outcome in the CCG OIS would be an important step in changing this. Employment rates amongst people with schizophrenia are low—at approximately 8%. We believe that more could be done to improve this, and that, with the effective implementation of interventions known to be successful, this could rise to 25% within a decade.

5.2 We also found a lack of access to peer support workers in Community Mental Health Teams,\textsuperscript{426} despite the fact that they were the second most popular non-pharmaceutical intervention by practitioners, service users and their families.\textsuperscript{427} That this intervention, which is also seen as having a positive influence on employment outcomes (for the service users and the peer support worker themselves) but again is often not available when wanted, and is not recommended in the NICE guidelines. Again, we would emphasise the importance of not focusing purely on the clinical aspect and symptom management of long term conditions.

5.3 Despite many of the people we interviewed as part of our research emphasising the importance of employment for them, they explained that their treatment was not personalised, with few clinicians asking what recovery meant for them. This often led to employment, an important issue for many people with a mental health condition, being left off the table when it came to discussing treatment. We believe that recovery should be about more than simply symptom reduction, even in cases of severe mental illness, and should be about the whole person.

6. EFFECTIVE INTERVENTIONS CAN COMBAT UNEMPLOYMENT AND REDUCE THE IMPACT OF LONG TERM CONDITIONS

6.1 Intervening early has repeatedly been demonstrated as key to higher rates of recovery. This in turn leads to a quicker and easier return to the labour market. This is particularly true in cases of severe mental health such as psychosis, in which the first three years are a critical period.\textsuperscript{428}

6.2 There is evidence to suggest that the Early Intervention in Psychosis (EIP) service model is particularly successful in prevent relapse and providing a useful intervention at this crucial stage. However, concern was raised by the healthcare experts we interviewed that the EIP model was being diluted due to funding and other pressures.\textsuperscript{429} We would argue that this is a false economy, given the long terms savings that EIP can provide in terms of employment outcomes, reduced suicide rate and a reduction in relapse and remission. In a report by the NHS Confederation it concluded that comprehensive implementation of EIP in England could save up to £40 million a year.\textsuperscript{430}

6.3 We would also encourage the committee to consider the strong evidence base for Individual Placement and Support (IPS)—a place then train model of employment support—which we believe to be one of the most effective methods of helping people with severe mental health conditions into employment.\textsuperscript{431}

\textsuperscript{423} Moussavi, S., Chatterji, S., Verdes, E., Tandon, A., Patel, V and Ustun, B. Depression, chronic diseases, and decrements in health: Results from the World Health Surveys (The Lancet, 370, 851–858, 2007)


\textsuperscript{426} Ibid


\textsuperscript{430} http://www.nhsconfed.org/Publications/Documents/early_interventionbriefing180511.pdf

6.4 The Work Foundation welcomes the government’s response to the “Independent Review of Sickness Absence”, and the creation of the Health and Work Assessment and Advisory Service (HWAAS). We believe that this service has the potential to make an important difference helping people to remain in work. This will lead to potentially better health outcomes, reducing long term costs to the NHS.

6.5 However, we were disappointed by the lack of reference to long term conditions and the recent response from Mr Hoban which stated that the service “will not be appropriate” for people with long term conditions.\footnote{Mark Hoban, Hansard—22 April 2013 Column 704w, http://www.publications.parliament.uk/pa/cm201213/cmhansrd/cm130422/text/130422w0006.htm} As we have already argued, the government cannot afford to ignore this group. The government must ensure that people with long term conditions are given the support they need to remain in work.

7. **MEDICAL INNOVATIONS MUST BE EXPLORED**

7.1 All clinical decisions affecting someone who wants to work need to be made through the lens of work as a possible clinical outcome. This includes decisions about use of medical technologies. Our report on medical technology, “Adding Value: The economic and societal benefits of medical technology” highlighted the conservatism in the NHS regarding the use of innovative medical technologies.\footnote{Stephen Bevan, Ksenia Zheltoukhova & Robin McGee “Adding Value: The economic and societal benefits of medical technology” (The Work Foundation, 2011, http://www.theworkfoundation.com/DownloadPublication/Report/296_Adding%20Value%20-%20The%20Economic%20and%20Societal%20Benefits%20of%20Medical%20Technology.pdf)} Whilst the research looked at a number of different medical technologies, this research found that insulin pumps for people with diabetes were a particularly useful but under-utilized intervention. We found evidence to suggest that not only can insulin pumps have important clinical benefits, but that it has the potential to improve employment rates in this group.\footnote{Ibid} There was also evidence that insulin pumps reduced the likelihood of other co-morbidities such as blindness, limb loss and kidney failure from developing.\footnote{Ibid}

7.2 We believe that this research clearly demonstrates a need to look at the long term impact of medical innovations such as insulin pumps when undertaking health technology assessments. Becoming too focused on short-term outcomes, not seeing the wider social policy picture, and failing to understand future benefits and cost-reduction, can lead to cultural conservatism when it comes to medical innovation. In a paper in December 2012, The Work Foundation—through its leadership of the Fit for Work Europe Coalition—examined the arguments for Health Technology Appraisal (HTA) taking a “societal” perspective. This would allow NICE, for example, to consider wider societal and labour market outcomes when assessing the benefits of treatments and therapies. Although progress seems to be being made towards this goal in the current Value-based Pricing negotiations, we believe that “work as a clinical” outcome for people with long-term conditions is more likely if HTA in the UK takes a wider societal perspective.\footnote{“Making work count—how Health Technology Assessment can keep Europeans in work” (Fit for Work Europe, 2012, http://www.fitforworkeurope.eu/Making%20work%20count%20-%20how%20HTA%20can%20keep%20Europeans%20in%20work_FULL%20PAPER.pdf)}

8. **CONCLUSION**

8.1 We welcome the Health committee’s decision to return to the subject of long term conditions, and look at the subject once again. This is a growing problem, for which the NHS and the UK at large must be prepared for. We urge the committee to bear in mind in their research the important role that employment plays in the live of people with long term conditions.

9 May 2013

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**Written evidence from Napp Pharmaceutical Group (LTC 70)**

**INTRODUCTION**

The Napp Pharmaceutical Group is a UK group of companies that is part of a worldwide network of independently associated pharmaceutical companies. The Napp Pharmaceutical Group manufactures and supplies medicines to the UK healthcare market, and exports medicines to our independently associated companies worldwide. We have a long heritage in the field of pain management, and have been supporting healthcare professionals to understand and manage chronic pain for over 30 years. In addition to the significant impact on individuals’ quality of life, poorly managed chronic pain places a financial burden on the NHS and the wider economy, which is why we continue to work towards better understanding and treatment. Our commitment to pain management extends beyond the provision of innovative medicines to include research into the impact of chronic pain on patients’ lives and further education for healthcare professionals in the management of pain.

\footnote{Mark Hoban, Hansard—22 April 2013 Column 704w, http://www.publications.parliament.uk/pa/cm201213/cmhansrd/cm130422/text/130422w0006.htm}
\footnote{Ibid}
\footnote{Ibid}
\footnote{“Making work count—how Health Technology Assessment can keep Europeans in work” (Fit for Work Europe, 2012, http://www.fitforworkeurope.eu/Making%20work%20count%20-%20how%20HTA%20can%20keep%20Europeans%20in%20work_FULL%20PAPER.pdf)}
1. Chronic Pain

We believe that given the scope of the Health Committee inquiry, chronic pain should be specifically included as it has been recognised as a Long Term Condition by Her Majesty’s Government, significantly impacts not only on individuals’ quality of life, but also their ability to function, work and is a central part of most of the key areas the Committee has already determined that they wish to examine.

1.1 Background

The 150th Chief Medical Officer’s report (2008) highlighted that:

- Each year over five million people in the United Kingdom develop chronic pain, but only two-thirds will recover.
- Chronic pain is the second most common reason for claiming incapacity benefit.
- 25% of sufferers lose their jobs.
- 49% of patients with chronic pain experience depression.
- Much more needs to be done to improve outcomes for patients. The significant numbers of people (7.8 million in the UK) living with chronic pain, the low pain specialist to patient ratio 1 to 32,000 and the poor resolution rates for pain in the UK.
- It has been estimated that back pain alone costs the economy £12.3 billion per year. The cost of pain from all causes is far higher.
- Chronic pain and its consequences are not as well controlled as they could be. Early intervention may stop pain becoming persistent.
- The limited number of specialist pain clinics around the country are inundated with referrals, and only 14% of people with pain have seen a pain specialist. Systems and infrastructure are not adequate to meet need or demand.
- Better coordination of services and services designed around the patient’s needs are essential.
- Chronic pain may be neglected at both ends of the age spectrum. In a study of United Kingdom nursing homes, most residents experienced constant or frequent moderate to severe pain, despite the fact that 99% were on pain medication.
- 16% of sufferers feel their chronic pain is so bad that they sometimes want to die.
- Each patient requires an early assessment.
- Each patient should have a tailored plan to suit individual needs.
- That all healthcare professionals training should include professional training in chronic pain.
- Consideration should be given to the assessment of pain in primary care and that pain should be part of the Quality and Outcomes Framework (QOF).

1.2 Pain frequently co-exists with other diseases or long term conditions such as diabetes and dementia (LTCs) and is sometimes mentioned as an element of care within disease management guidelines such as the NICE Cancer guidance or dementia quality standards (QS).

Chronic pain has been the subject of two recent House of Commons questions.

In a statement in response to a question asked in the House of Commons on the 1st February 2012 by Linda Riordan MP, to ask the Secretary of State for Health whether it is his policy that chronic pain is a long-term condition that requires the preparation of care plans.

Chair Paul Burstow MP responded:

The Department recognises chronic pain as a long-term condition, either in its own right or as a component of other long-term conditions. Everyone who suffers persistent pain should have a timely assessment in order to determine the cause of the pain—if a cause can be determined—and to advise on options for treatment, including self-help. Patients with refractory chronic pain will benefit from the care planning approach, but decisions should be taken on an individual basis depending on the severity of symptoms and any co-morbidities.

1.3 Further on the 24th April 2013, Huw Irranca-Davies: to ask the Secretary of State for Health pursuant to the contribution by the Minister of State for Care and Support on 25 February 2013, Official Report, columns 147–150, what plans he has to introduce a quality standard for chronic pain management.

Norman Lamb: The Department has asked the National Institute for Health and Care Excellence (NICE) to develop a quality standard on pain management for young people and adults as part of a library of approximately 180 NHS Quality Standards. NICE has not yet published a time scale for the development of this quality standard. NHS England is now responsible for the strategic direction of NHS quality standards.

438 http://www.publications.parliament.uk/pa/cm201213/cmhansrd/cm130424/text/130424w0005.htm#130424w0005
439 http://www.publications.parliament.uk/pa/cm201213/cmhansrd/cm130424/text/130424w0005.htm#wqn3
1.4 The mandate to NHS England requires it to deliver continued improvements in relation to enhancing the quality of life for people with long-term conditions, which includes those with chronic pain.

1.5 On the 4th July 2012, “Putting pain on the Agenda”, the report of the first English Pain Summit was launched in the House of Commons. Four key recommendations were agreed:

1. Clear standards and criteria must be agreed and implemented nationally for the identification, assessment, and initial management of problematic pain
2. An awareness campaign should be run to explain the nature, extent, impact, prevention and treatment of chronic pain to the wider general and NHS community
3. Nationally-agreed commissioning guidance must be developed and agreed, describing best value care in chronic pain to reduce unwarranted variation
4. A data strategy for chronic pain should be agreed through creation of an epidemiology of chronic pain working group

1.6 However despite there being recognition by the Government that chronic pain should be considered as a LTC in its own right during 2012, and significant recognition regarding the appropriate management of chronic pain in the United Kingdom, there has been little activity to develop a specific Quality Standard, include it within the Quality Outcomes Framework or within the clinical domains of the NHS outcomes framework.

There is also variance of pain status across the devolved nations eg Scotland recognising it as a specific condition in its own right with SIGN guidelines currently being developed.

Pain is also poorly recognised, diagnosed and under managed in vulnerable patients with conditions such as dementia. Improvements here would clearly demonstrate “compassionate care”.

9 May 2013

Written evidence from the British Pain Society and the RCGP Clinical Champion for Chronic Pain (LTC 71)

We wish to draw the attention of the Health Select Committee to the fact that chronic pain has very limited visibility and prioritisation in the Long Term Conditions agenda. This is despite pain being recognised in parliament as a Long Term Condition on the 1st February 2012 (www.publications.parliament.uk/pa/cm201212/cmhansrd/cm120201/text/120201w0002.htm).

Two recent high level reports, both published in December 2012, The National Pain Audit and the Health Survey England, were acknowledged and reported by Sir Bruce Keogh in one of his recent bulletins http://mdbulletin.dh.gov.uk/2013/01/23/chronic-pain-audit/

The Health Survey for England revealed more than 14 million sufferers of chronic pain. The study found that pain is more common among some groups than others, incurs significant costs and has serious mental health and wellbeing implications.

The National Pain Audit showed the quality of life that chronic pain patients endure (average quality of life score (EuroQol) 0.4) is extremely low and also the inequity in the wide variation of availability and types of pain services that are available across England. On a positive note the audit showed the benefit of patients attending chronic pain services.

We would contend that chronic pain is one of, if not the commonest Long Term Condition, but as yet there is no suggestion that it should be part of routine care planning for patients who are having the rest of their multiple co-morbidities frequently assessed.

We would ask the Health Select Committee to review this issue.

The British Pain Society or the RCGP Clinical Champion for Chronic Pain would be happy to appear before the Committee to give further evidence regarding this enormous problem.

9 May 2013

441 http://www.policyconnect.org.uk/sites/default/files/Putting%20Pain%20on%20the%20Agenda.pdf
Written evidence from the AntiCoagulation Self-Monitoring Alliance (LTC 72)

1. ABOUT THE ANTI CoAGULATION SELF-MONITORING ALLIANCE (ACSMA)

1.1 The AntiCoagulation Self-Monitoring Alliance (ACSMA) was established in October 2012 with the objective of achieving greater access to self-monitoring technology for people who are on long-term warfarin and for self-monitoring technologies to be available on NHS prescription.

1.2 ACSMA comprises four of the UK’s leading charities and patient groups—AntiCoagulation Europe; the Children’s Heart Federation; AF Association; Mechanical Heart Valve Support Group—that exist to provide advice, support and guidance to people on oral anticoagulation therapy, as well as their families and healthcare professionals. Healthcare company Roche is also part of the alliance.

1.3 ACSMA is campaigning for greater choice for people on long-term warfarin about how their condition is managed. Our goal is to enable people—wherever possible, allowing those on long-term warfarin the option to self-monitor their condition. ACSMA is also seeking to raise awareness and to ensure that people are equipped to have informed discussions with their healthcare professionals on this topic.

1.4 We believe that these changes will improve health outcomes, patient choice and convenience, as well save time and money for both individuals and the NHS.442,443

2. EXECUTIVE SUMMARY

2.1 We welcome the Health Committee’s Inquiry into the Management of Long-Term Conditions, as this topic is one of vital importance for ACSMA and our campaign. Sections 4–8 set out in more detail our thoughts and comments in relation to the specific terms of reference for this Inquiry.

2.2 The key points of our submission can be summarised as follows:

2.2.1 People with long-term conditions should have the choice to self-monitor their condition. For people on long-term warfarin, this must include having access on NHS prescription to the technologies that can help them achieve that, as well as appropriate support and guidance from their healthcare professional. NHS service commissioners and providers need to look to how anticoagulation services can be redesigned; liberated from the hospital and primary care clinics to enable those who wish to take control of their treatment to do so, and to manage their treatment in a way that suits them, their families and their lifestyles.

2.2.2 People with long-term conditions should be managed holistically, as a whole person, rather than treated exclusively for their condition. Although it has been said many times before, a more patient-centric approach really is needed. More clinical services and experts sharing community clinics and managing patients holistically would encourage the sharing of knowledge.

2.2.3 The current assessment of ongoing care needs should be revised. Anticoagulation is a vital part of the ongoing health of our society, whether that is by preventing ill health (by preventing a stroke or thrombosis, for example) or by maintaining the benefits of intervention already undertaken. The importance of effective anticoagulation in terms of disease prevention becomes even more important in the context of an ageing society. Recent NICE guidance has shown that current care is sub-optimal and that the assessment of ongoing care needs should be revised. ACSMA supports this, not only because it will lead to better long-term care, but also because of the opportunities for life-long intervention for those most at risk of a thrombotic event.

2.2.4 There is a lack of knowledge on the part of both patients and healthcare professionals about the self-management of long-term conditions. Addressing this education gap is vitally important and a real priority. Patient education needs to be improved so people can, if they choose, take control of their condition. Clinicians should be educated so they can have informed discussions with their patients about the opportunities that exist and the suitability of one regime over another, and to understand how they can best support patients who choose to self-monitor.

2.2.5 There is an urgent need to address the disconnect between national Government policy—which is supportive of greater self-management and choice for people with long-term conditions—and poor implementation of those policies at local NHS level. Patient choice has been the holy grail for many years now and yet our members and supporters tell us numerous stories of healthcare professionals who refuse to discuss self-monitoring with them, claiming that it is illegal, “not allowed here” or would render the healthcare professional liable to litigation were something to go wrong. We are aware of some localities where clinics refuse to prescribe the strips for the INR monitors, or threaten to refuse to prescribe the warfarin itself, to those patients keen to try self-monitoring. In the meantime, the Government continues to support the principle and practice of self-management through its “3million lives” initiative, the Mandate to NHS England and other policies such as “Innovation, Health and Wealth”.


2.2.6  At present, an estimated 2% of the 1.2 million on long-term warfarin are self-monitoring their blood clotting levels.\textsuperscript{444} If more people were able to do so, the savings to the NHS would be substantial. Current estimates show that the management of oral anticoagulation therapy for patients with stable conditions costs the NHS approximately £409 million\textsuperscript{445}. Studies show that if the estimated 1 in 4 self-monitored, the NHS could save up to £62 million a year\textsuperscript{446}.

3. ANTICOAGULATION THERAPY MANAGEMENT

3.1 People on long-term warfarin need to have regular blood tests to check their internationalised normal ratio (INR), or level of clotting tendency. These blood tests are usually conducted in a hospital outpatient clinic or GP surgery, where the warfarin dose can be adjusted, if required. The time needed to attend regular clinic appointments can quickly begin to affect a person’s personal and professional lives; whether they are in full time work, education or are parents of a child on long-term warfarin.

3.2 Evidence shows that there are currently more than 1.2 million people in the UK on warfarin.\textsuperscript{447,448} This might be due to a previous stroke, a venous or pulmonary thromboembolism, a deep vein thrombosis—or to prevent a recurrence thereof—or because of atrial fibrillation or the fitting of a mechanical heart valve. Of these, less than two% current benefit from self-monitoring\textsuperscript{449} despite evidence that it can cut the risk of death by nearly two-fifths\textsuperscript{450} and more than half the risk of strokes.\textsuperscript{451}

3.3 In all areas where anticoagulation therapy is recommended by guideline and good clinical practice, the benefits to patients in terms of the reduction of clinical risk are substantial. These benefits are without consequence; anticoagulant therapies are not without risk if not monitored appropriately or poorly controlled. For that reason, the solution for anticoagulation provision to date has largely been hospital and clinic-based. Our evidence is that anticoagulation clinics in NHS hospitals are struggling to cope with the volume of people that attend and, although many of these services are of a high quality, both patients and clinicians have been known to make decisions regarding the choice of intervention based what is convenient for the clinic, rather than what is best for the patient.

Turning now to the Inquiry’s terms of reference:

4. THE SCOPE FOR VARYING THE CURRENT MIX OF SERVICE RESPONSIBILITIES SO THAT MORE PEOPLE ARE TREATED OUTSIDE HOSPITAL AND THE CONSEQUENCES OF SUCH SERVICE RE-DESIGN FOR COSTS AND EFFECTIVENESS

4.1 Currently, the provision of anticoagulation monitoring is largely restricted to clinics and hospitals with, as noted above, only a very small percentage of people on long-term warfarin being given the opportunity to self monitor their INR levels at a convenient time to them. As a result, many people who have been returned to good health by some form of clinical intervention (for example, following a stroke) or who have received an intervention to prevent them from further poor health find their lives governed by clinics. This is inconvenient for people on warfarin and their families, as well as costly for the NHS.

4.2 ACSMA supports moves that would allow people on long-term warfarin to self-monitor their INR levels outside a hospital setting using portable INR testing devices. NHS service commissioners and providers need to look to how anticoagulation services can be liberated from the hospital and primary care clinics to enable those who wish to take control of their treatment to do so, and to manage their treatment in a way—and at a time and place—that suits them, their families and their lifestyles.

4.3 A change to service responsibilities must ensure that people have better access to the technologies that will help them self-monitor their condition and this should include flexibility in how and where they are managed and by whom. The technologies to do so have been available (albeit at the patient’s cost) for many years and the diagnostic strips are currently available on NHS prescription. Ensuring better access must include making the self-monitoring devices available on NHS prescription to those who are willing and able to use them, as well as preventing healthcare professionals and clinics from refusing to prescribe either the device or the testing strips on anything other than clinical grounds.

4.4 Any redesign of services for a non-clinical (community or home) setting should also take account of the following factors:

— Management of conditions in the community needs to be consistent—with standards of care being monitored and measured in every setting according to key performance metrics.

\textsuperscript{451} Ibid.
4.5 There are cost implications of redesigning services to empower patients in this way. However, the potential for redesigning anticoagulation services to achieve cost offsets and savings is considerable. Current estimates show that the management of oral anticoagulation therapy for patients with stable conditions costs the NHS approximately £409 million.\(^{452}\) As noted above, if just one in four self-monitored, the estimated savings to the NHS would be substantial, even taking into account the cost of funding both the INR monitoring device and the test strips on NHS prescription. ACSMA is aware that there is ongoing work to model the likely cost savings to the NHS, based on the latest trial data. We would be happy to share further details of this work if that would be helpful to the Committee.

4.6 As noted below (paragraph 6), this issue will become even more critical with an increasing ageing population that will stretch existing anticoagulant services even further.

5. The Readiness of Local NHS and Social Care Services to Treat Patients with Long-Term Conditions (Including Multiple Conditions) within the Community; and the Ability of Providers to Treat Multi-Morbidities and the Patient as a Person rather than Focusing on Individual Conditions

5.1 In our opinion, these two points go hand-in-hand. A readiness to treat people with long-term conditions in the community will be determined by having the right policies, processes and resourcing in place. This can be facilitated by NHS and social care services adopting a patient-centric approach, where the individual is treated as a whole person, rather than as a “patient” with a particular condition.

5.2 There is a need to have more clinical services and experts sharing community clinics and managing the patient holistically and encouraging sharing of knowledge. For example, specialist nurses and doctors could be trained to specialise across two or three common disease areas with consultants dealing with more serious cases. As noted below, there is a dearth of specialist clinicians working in communities who are able to offer personalised services. This needs to change.

6. The Implications of an Ageing Population for the Prevalence and Type of Long-Term Conditions

6.1 As the population ages and acute health services become more adept at allowing people to survive acute cardiac and thrombotic events, the need for effective and adaptable anticoagulation services becomes ever more important—particularly for the prevention of ill-health and to prevent disease recurrence.

6.2 To give one example, the incidence of the heart rhythm disorder atrial fibrillation (AF) is increasing. The current national prevalence of AF is 1.72%, with a massive prevalence of over 10% of the over 65 population.\(^{456}\) AF carries a five-fold increase in the risk of stroke, with one in three people with AF suffering a stroke within their lifetime.\(^{454}\) Currently, 15–20% of ischaemic strokes are related to AF;\(^{455}\) and these strokes have been shown to carry a much higher level of an ongoing disability and also mortality.

6.3 Well-managed anticoagulation therapy reduces the risk of stroke by nearly 70%.\(^{456}\) Several studies\(^{457}\) have shown that patient self-monitoring can improve the quality of oral anticoagulant therapy, with those who self manage having fewer thromboembolic events and lower mortality rates. Specifically, there is evidence that self-monitoring can cut the risk of death by nearly two-fifths\(^{458}\) and more than halve the risk of strokes.\(^{459}\)

6.4 National and regional guidelines and the National Quality and Outcomes Framework (QOF) are directing providers to treat multi-morbidities and the patient as a person rather than focusing on individual conditions. As noted above, if just one in four self-monitored, the estimated savings to the NHS would be substantial, even taking into account the cost of funding both the INR monitoring device and the test strips on NHS prescription. ACSMA is aware that there is ongoing work to model the likely cost savings to the NHS, based on the latest trial data. We would be happy to share further details of this work if that would be helpful to the Committee.

6.5 The incidence of valvular heart disease is also increasing. Many people with this condition require long-term anticoagulation therapy. Although there have been innovations in the range of oral anticoagulants available, these are not suitable for those with valvular disease. Consequently, people remain dependant on warfarin and the need for ongoing INR monitoring. Predicting the needs of an ageing population based on statistical data will confirm key areas of focus.

\(^{453}\) Bayer Health Care Pharmaceuticals. Taking the pulse of NHS services; stroke prevention and atrial fibrillation. December 2012.
\(^{454}\) Ibid.
\(^{455}\) Ibid.
\(^{456}\) NHS Information Centre. The percentage of patients with atrial fibrillation who are currently treated with anti-coagulation drug therapy or an anti-platelet therapy QOF 3.
\(^{459}\) Ibid.
7. THE PRACTICAL ASSISTANCE OFFERED TO COMMISSIONERS TO SUPPORT THE DESIGN OF SERVICES, WHICH PROMOTE COMMUNITY-BASED CARE AND PROVIDE FOR THE INTEGRATION OF HEALTH AND SOCIAL CARE IN THE MANAGEMENT OF LONG-TERM CONDITIONS

7.1 Despite the obvious benefits, data indicates that many current anticoagulation services are sub-optimal.\textsuperscript{461} A NICE 2006 costing report on AF estimated that 46\% of patients who should be taking anticoagulation therapy are not currently receiving it, and those who do receive it are not in optimal therapeutic range.\textsuperscript{462}

7.2 Practical assistance for service commissioners could involve identifying the prevalence and incidence of people requiring anticoagulation services in a local health economy; a national patient experience survey of people using anticoagulation services; incentives and payments directed more towards prevention of ill-health; and engaging with patients and service users in service design.

8. THE EXTENT TO WHICH PATIENTS ARE BEING OFFERED PERSONALISED SERVICES

8.1 ACSMA believes that there is considerable variation and inconsistencies in how care plans are being used for those receiving anticoagulation therapy. There is a lack of specialist clinicians working in communities who are able to offer personalised services. This is due to a variety of reasons, including a limited scope of responsibilities, the costs involved, lack of incentives (payment) and the resourcing required.

8.2 Our experience is that we have a long way to go before patient choice and personalised care become a reality. There is an urgent need to address the disconnect between national Government policy—which is supportive of greater self-management and choice for people with long-term conditions—and poor implementation of those policies at local NHS level.

CONCLUSIONS

9. Anti-coagulation is a vital part of the ongoing health of our society, whether that is by preventing ill health, or in maintaining the benefits of intervention already undertaken. However, current service provision is sub-optimal and organised around the needs of the clinic, not the patients. If more people on long-term warfarin were able to self-monitor their INR levels, the benefits in terms of health outcomes, patient choice and the savings to the NHS would be considerable. Raising awareness of self-monitoring and making the devices available on NHS prescription are both key to achieving these benefits.

10. ACSMA would welcome the opportunity to give oral evidence to the Committee’s inquiry, if that would be helpful.

10 May 2013

Written evidence submitted on behalf of Roche Diagnostics UK (LTC 73)

SUMMARY

1. Long-term conditions, defined by the Department of Health as “conditions that cannot, at present, be cured but can be controlled by medication and other therapies” have a major impact on quality of life, disability and are the main cause of premature death in England; they also account for a significant proportion of NHS expenditure.

2. The NHS has been largely successful at tackling Beveridge’s “giant” of disease, therefore long-term conditions will assume greater absolute and relative importance. The challenge now is to support the nearly one in three people—over 20 million in England—who have at least one long-term condition: whether diabetes, coronary heart disease, etc. or as a survivor of cancer treatment.

3. This challenge highlights two major concerns: whether the NHS in its current form (largely funded through general taxation with access free at the point of use) is affordable—people with long-term conditions account for 70\% of expenditure on health and care; and whether the current model with its emphasis on the investment in the provision of treatment by medical practitioners in acute care settings is appropriate for people with long-term conditions.

4. This submission, whilst recognising the need for a paradigm shift, such as those advocated by Wagner\textsuperscript{463} (1998) and Kane et al\textsuperscript{464} (2005) to a Chronic Care Model; and emphasis on evidence-based preventative interventions such as nutrition and physical activity, advocates that the use of technology facilitating self-management by people with long-term conditions in an integrated health and social care system is an integral part of the solution.


\textsuperscript{463} Wagner E (1998) “Chronic disease management: what will it take to improve care for chronic illness?” Effective Clinical Practice, 1: 2–4

INTRODUCTION

5. People with long-term conditions are often the most important primary care provider, where long-term conditions are a major burden of disease (Sobel, 1995). Given that most care has always been self-care, any reduction in self-management will result in a potentially insupportable burden on health and care services. The Expert Patient Programme in England demonstrated the benefits of self-management support (Kennedy et al 2007).

6. Over the past ten or so years, government policy has sought to shift emphasis towards a primary care led NHS as part of a move towards an integrated health and care system, with emphasis being placed on fostering a more person-centred approach to care, taking a holistic view of an individual’s needs to help them live as independently as possible.

7. The Quality and Outcomes Framework (QOF) introduced in 2004 provides a financial incentive for GPs (10–15% of the remuneration) based on achieving a range of nationally set quality-based targets focused on ill-health prevention through the effective management of people with, or at risk of, developing a range of long-term conditions. QOF incentive payments have already been shown to have a positive impact on the nature and quality of care (Campbell et al 2007).

8. Consideration should be given to extending or looking at similar incentives to achieve the “paradigm shift”, recognising that this will require disinvestment elsewhere in the system. At a policy level, we have seen the integrated care pilots established as part of the NHS Next Stage Review, and more recently, the Health and Social Care Act 2012 places a duty on providers to work more closely together to address these issues.

9. Ham identifies ten characteristics of a “high-performing chronic care system” (Ham, 2010). These include: “priority is given to patients to self-manage their conditions with support from carers and families”, “priority is given to primary health care” and “the need to exploit the potential benefits of information technology in improving chronic care”.

10. Below are three examples of patient groups who take a leading role in the day-to-day management of their condition; where self-monitoring is helping them stay healthy, reducing complications and generating savings for the NHS.

WARFARIN MONITORING

11. Warfarin is the main oral anticoagulant used in the UK. Anticoagulant medicines are most commonly prescribed for people who have had a condition caused by a blood clot (thrombosis) or are at risk of developing one. These conditions include:

- deep vein thrombosis (DVT);
- pulmonary embolism; and
- atrial fibrillation (AF).

12. Warfarin may also be prescribed for people with a replacement or mechanical heart valve.

13. There are more than 1.2 million people in the UK on warfarin (Gardiner et al, 2004, ONS). Connock et al (2007) estimated that numbers continue to increase by about 10% each year, primarily driven by its use for patients with atrial fibrillation. The future impact of this expansion is indicated by estimates that currently more than half of those with atrial fibrillation may remain unidentified and less than half of those identified may be receiving treatment. These estimates considered together with an ageing population mean that future service load could increase substantially.

14. However, it is estimated that fewer than two% of them benefit from self-monitoring (Roche data). Self-monitoring has been shown to reduce the risk of stroke by over 50% and reduce mortality rates by nearly two fifths (Henegan et al, 2006). Better access to self-monitoring of international normalized ratio (INR) levels, which measures how long it takes blood to form a clot, could also reduce the number of complications. Current estimates show that oral anticoagulation therapy (OAT) management of stable patients costs the NHS around £409 million (Fitzmaurice et al, 2005, NICE). Studies also show that if only one in four

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469 Gardiner et.al. Patient self-testing is a reliable and acceptable alternative to laboratory monitoring. Br J Haem 2004; 128:242–47
patients took up self-monitoring (Connock et al, 2007) this would save the NHS approximately £62 million per year (Roche data).475

15. The CoaguChek XS is a Point of Care (POC) device used by competent patients to monitor and manage their INR levels, thereby reducing the burden on NHS resources. The device uses blood sample from a finger prick applied to a testing strip. The result is displayed within a minute of applying the blood sample, and if needed, adjustments to warfarin dosage made. This gives the patient more freedom to travel and avoids disruption to work and home life that potentially frequent visits to anticoagulation clinics can cause. Patient self-management can—and where appropriate should—empower the patient to determine the dose adjustment with the support of resources, such as dosing charts and access to advice if required.

DEEP VEIN THROMBOSIS

16. Deep vein thrombosis (DVT) is a cause of 25,000 deaths in the UK each year and can lead to the development of post-thrombotic syndrome (PTS) with chronic swelling and ulceration of the legs (Health Committee 2004/5).476 DVT can be clinically very difficult to diagnose but early recognition and appropriate treatment can improve clinical outcomes.

17. In response to the National Guidance on Care Close to Home (NHS Local 2010)477 in May 2010 a DVT service was initiated at Solihull Healthcare and Walk-in Centre which enables uncomplicated DVT identification and management using D-dimer testing, hastening patient care and avoiding referrals to hospital. In the first 11 months of the service, 355 patients were tested for DVT, saving in excess of £220,000 from reduced hospital admissions, with feedback showing an improved patient experience. The Cobas® H232 D-Dimer diagnostic test is a point of care (POC) blood test that can be carried out in primary care and can be used to rule out VTE. The sample required is from a finger prick and a result is given within eight minutes.

18. Similarly, in 2009 South West Essex community services, now part of North East London Foundation Trust, established a DVT service based at Brentwood Community Hospital aimed at improving DVT diagnostic services for nine GP practices in the Brentwood area, serving a population of 74,000. The DVT service sees on average 250 patients per year. With each acute DVT presentation costing approximately £500 per patient if referred to secondary care. However, all patients can now be assessed and managed in primary care with an approximate annual saving of £60,000. Savings are also made in time, as well as in costs. Following a suspected DVT referral to the Community Hospital it takes approximately 30–60 minutes for a patient to be seen and assessed, including carrying out the D-dimer test—patients report that being able to have their condition assessed more rapidly and in a primary care setting is much less stressful for them.

DIABETES CARE

19. Diabetes is a long-term chronic condition caused by too much glucose (sugar) in the blood. There are two types of Diabetes: Type 1 occurs when your immune system destroys the beta cells in the pancreas that create insulin. As a result, the body makes very little or no insulin of its own. People with Type 1 diabetes must take insulin daily. In Type 2, not enough insulin is produced or the insulin that is made by the body doesn’t work properly. Type 2 diabetes can affect people at any age.

20. According to Diabetes UK, between 2006 and 2011, the number of people diagnosed with diabetes in England increased by 25%, from 1.9 million to 2.5 million. There has also been a huge growth in complication rates during this time. Diabetes is now the biggest single cause of amputation, stroke, blindness, and end-stage kidney failure. The reality of any of those devastating outcomes for patients demonstrates the NHS is not able to plan for or manage the realities of long-term diabetes outcomes, including the multiple conditions a person with diabetes is likely to develop in the later stages of having the condition.

21. While there have been some demonstrable improvements in diabetes care since the National Service Framework for Diabetes was first introduced in 2001, annual National Diabetes Audits indicate there remains is a great deal of work to do, including tackling poor provision of structured education and increased delivery of personalised diabetes care.478

22. Considering current diabetes spend accounts for around 10% of the NHS budget, we need to ensure that everything is being done to encourage patients to maintain good diabetes control.

SELF-MONITORING OF BLOOD GLUCOSE (SMBG)

23. Monitoring blood glucose is a very important part of managing diabetes. Regularly testing blood glucose helps measure the effectiveness of a patient’s dietary planning, exercise and medication, with good control helping reduce longer-term complications. In order to self-test blood glucose, a patient needs a blood glucose meter, a test strip and a finger pricker.

475 This figure takes into account all secondary care costs, primary care costs and costs of the CoaguChek XS device and test strips
24. In England, the blood glucose meter and finger pricker is provided free through the NHS via a healthcare professional. Test strips are then provided on prescription, with the number of tests allocated based on the frequency of testing required eg depending on the type of diabetes you have, your level of physical activity and how frequently you drive.

25. Unfortunately, short-term financial savings by CCGs are, in an increasing number of incidences, threatening self-management, for example, restrictions around access to blood glucose test strips or inconsistent formulary processes/decisions surrounding the type of blood glucose meter made available to patients.

26. There are 250,000 people with Type 1 diabetes in England. Their lives depend on insulin injection or pump treatment, which requires them to regularly carry out self-blood glucose measurements (SBGM), normally several tests a day eg upon waking, before/after eating and before bed.

27. However, people with Type 1 diabetes are increasingly being restricted access to test strips. In a letter circulated to General Practitioners, Hospital Doctors, Community Pharmacists and PCT Chief Executives in February 2013, the National Clinical Director for Diabetes reaffirmed the importance of testing, stating it is “essential that people with Type 1 diabetes are prescribed sufficient SBGM testing strips for their clinical needs (as outlined in NICE guidance CG15, TA 60). This enables people with diabetes to self-manage, recognising the symptoms of Diabetic ketoacidosis, encouraging them to take early action and seek help, especially if it involves driving.

28. The letter also clarified that “While testing strips dispensed in primary care may appear to have a premium cost, the wider costs to the patient’s quality of life, their safety and ability to work and to the NHS of complications of uncontrolled diabetes far outweigh these costs, including the cost of repeated unplanned A&E admissions. Further costs for the strips in most cases also include provision of educational material, meters, and helplines for patients by the manufacturer.”

ACCESS TO INNOVATIVE BLOOD GLUCOSE METERS

29. Recent advances in technology have made insulin bolus advisors available to patients on multiple daily injections (MDI). Bolus advisors support patients on MDI, using a long acting basal insulin analogue to achieve optimal diabetes control. Individually programmed, patients can just test their blood glucose levels with the system, enter the carbs they are about to eat and receive bolus advise.

30. An online user survey of patients showed that the majority of respondents felt using the bolus advisor improved confidence in the accuracy of the mealtime bolus insulin dose and reduced their fear of hypoglycaemia. Patients found the system easy and motivating to use with 72% respondents reporting overall wellbeing/life with diabetes had improved or significantly improved since using their bolus advisor, with greater confidence and control in their diabetes management.

ACCESS TO INSULIN PUMP THERAPY

31. The role of insulin pumps for Type 1 diabetics is recognised worldwide and has been endorsed in the UK by NICE. The use of insulin pumps in the UK remains low compared to other developed nations, however, in the last four to five years we have seen a significant rise in the numbers of pumps being used.

32. Working in partnership to improve pump uptake, Roche has made a significant contribution to this growth through a complete service offering for our NHS partners from patient/healthcare professional education through to a 24 hour careline for our patients. Our educational pump courses have helped to train over 250 DSNs on the practicalities and benefits of pump therapy helping to expand the number of centres offering pump therapy. We believe our work has helped many 100s of patients gain access to pump therapy who wouldn’t otherwise have done so.

COMMISSIONING SUPPORT

33. Practical assistance for commissioners to support the design of local diabetes services have in past been provided by NHS Diabetes. While that best practice remains relevant, Roche Diabetes Care is concerned the closure of NHS Diabetes and poor awareness of their previous work will leave CCGs and commissioners without the necessary information required to understand and appropriately design and commission high-quality diabetes services.

34. While the NHS Diabetes website will be kept open for several months, we would like to see the expert knowledge and best practice transferred and made available on the new NHS Improvement website, with commissioners being encouraged to engage with existing best practice.


CONCLUSION

35. Long-term conditions account for: 50% of GP appointments, 70% of bed days and 70% of health and care budgets.

36. The technology for self-monitoring and management is available. Remote and other forms of diagnostic monitoring are being further developed to support self and directed management approaches.

37. However, the uptake of innovative technology by the NHS is slow. Whilst recognising that to derive the maximum benefits from the use of such technology, services must be redesigned—and not just to realise the potential savings or to release resources for reinvestment—but to achieve the holistic benefits for the individual, as well as society as a whole, the examples above show what can be achieved within the current NHS and social care model. The potential for the use of such technology within a new model of care, such as the Chronic Care Model, is arguably greater still.

ABOUT ROCHE DIAGNOSTICS UK

38. Roche Diagnostics is the world’s largest in vitro diagnostics company, supplying high quality products and services which are used to diagnose and monitor medical conditions and facilitate medical research. From small devices used directly by patients or healthcare professionals, to large diagnostic instruments found in hospital laboratories, Roche has a track record of developing new and innovative devices.

39. Roche has pioneered the development of hand held systems, empowering patients with diabetes and those receiving anticoagulation therapy, to monitor their own long-term conditions easily and accurately. Roche Diabetes Care’s Accu-Chek® brand is the world leader in diabetes care, with a diverse portfolio of products designed to help people with diabetes live healthy, productive lives and to make managing diabetes easier.

9 May 2013

Written evidence from Janssen (LTC 74)

INTRODUCTION

1. Janssen is the Pharmaceutical Operating Company of the Johnson & Johnson family of companies. Johnson & Johnson is the largest healthcare company in the world and has a tradition of commitment to the UK, being established in the UK since 1927. Today, Johnson & Johnson employs circa 5,000 people across the UK. We have manufacturing sites in Inverness, Blackpool, Livingston, Cardiff and research and development facilities in Inverness, Leeds, and High Wycombe.

2. We are committed to delivering innovative medicines which make an important difference to the lives of patients with serious health conditions such as hepatitis C, HIV, schizophrenia and cancer. Janssen is committed to providing medicines that have a real impact on the lives of patients and reduce health inequalities. We welcome the opportunity to respond to this inquiry.

3. We are pleased that diabetes and severe mental health conditions are recognised as areas that need to be reviewed as part of this inquiry.

4. Janssen also believes that there are further conditions that should be considered within this enquiry, including psoriasis and HIV.

5. As recognised by the inquiry, all long-term conditions (LTCs) present a huge burden to the NHS and social care system accounting for 70% of health and care spend, affecting over 20 million people in England, however equal recognition should be given to the impact of caring for someone with a LTC. Provisions for carers should be examined by the Health Committee as they play an integral role in delivering care and treatment to those affected.

6. Integral to the management of all LTCs is the need for excellent patient information and support. In the advent of the recent NHS reforms, it is crucial that attention is given to the provision of accurate, reputable advice on how to manage a LTC. This information can be used to empower a patient (or their carer) to take responsibility for their own condition and optimise their personal management.

7. It is critical that patients have access to cost-effective innovation as part of an integrated pathway of care and that CCGs are measured, incentivised and rewarded for delivering excellence in the care of patients with LTCs. Uptake of new technologies that improve outcomes must be central to this in the new NHS.

DIABETES

8. The scale of the challenge that diabetes presents in the UK should not be underestimated, with high, recorded prevalence of diabetes and associated co-morbidities across the country, as well as high estimations of undiagnosed populations. Early diagnosis, preventative treatment and multi-disciplinary team support of the
patients will undoubtedly mean increased financial pressure in the short-term; however, leaving these patients undiagnosed until further complications ensue will result in a heavier total cost burden to the NHS.

9. It is fundamentally important to have clear consistent processes across all CCGs in place for early diagnosis and management of diabetes, with plans which are specific and measurable. Short-term investment in early detection, diagnosis and good management will lead not only to good practice, but also long-term savings resulting from avoiding complications and late identification of the disease.

10 The planning of future services in diabetes should include performance reports measured against outcomes, with indicators and performance measures published regularly and made available in the public domain. Significant resource investment and support will be required to have an impact on the problems that occur due to diabetes. Additionally, through working in innovative ways with partners, both within NHS England and outside, huge improvements can be achieved. Janssen is committed to providing solutions in diabetes and would be supportive of initiatives that address the challenges.


11. In summary, Janssen believe that diabetes care is too often varied and inconsistent with unnecessary failings continuing to occur. To prevent these instances from happening, better training and education for all healthcare professionals throughout the NHS should be introduced. Due to the epidemic proportions of people affected by diabetes, it is imperative that education addresses how diabetes should be observed and monitored in patients with multiple morbidities.

Schizophrenia

12. For over 50 years, Janssen has continually invested in medicines to improve the lives of people with devastating and disabling mental health conditions. Although medicines have improved during this time, people with conditions such as schizophrenia and ADHD still face challenges in staying well and living long active lives. Compared with physical health conditions, mental illness is still seen as the “Cinderella” of the health service. Janssen is committed to working with mental health and neurological services to continually challenge the current status quo to improve the lives of everyone involved.

13. Janssen is broadly aligned to the findings of the recent Schizophrenia Commission report entitled “The Abandoned Illness” (www.schizophreniacommission.org.uk) and the 42 recommendations highlighted within it. While ensuring access to medicines is optimised for patients affected by schizophrenia, other aspects of care are integral to improving the treatment pathways and support for this patient group.

In summary, Janssen supports the notion that people with schizophrenia need:

- Access to talking therapies.
- Proper attention to physical health because of their reduced life expectancy (10–15 years).
- Practical support to assist recovery.
- Access to the best medication.

14. As an organisation we are aligned to all the themes covered by the report from the Schizophrenia Commission and believe that this should provide the foundation for the Inquiry to refer to and act upon. Key asks include:

14.1 Improved provision for the genuine involvement of the patient and his/her carer in decisions relating to their treatment and care, wherever possible.

14.2 Reduced stigma—for the people affected by schizophrenia, the illness itself and its treatment.

14.3 Reduced inequality—both geographical inequity in the quality of care patients receive, but also versus investment for physical health conditions, not affected by the same taboos and stigma of schizophrenia and other serious mental illness.

14.4 Improved regularity and robustness of evaluation and accountability for achieving outcomes.

14.5 Encouraged early intervention to improve long-term outcomes in people with schizophrenia.

14.6 Established and well integrated services to facilitate increased and better quality care in the community.

14.7 Apart from holistic treatment, an established and tangible means to help people with schizophrenia to restore a meaningful life, such as initiatives to help them return to work.

14.8 Incentivised organisations who invest and work together to research new treatments for schizophrenia.

15 Following the publication of “The Abandoned Illness” report, Janssen is particularly supportive of the following recommendations that would improve the treatment and care for this patient group:

15.1 We recommend that the Work Capability Assessment process is amended for people with schizophrenia and psychosis to require the Department for Work and Pensions to seek information
from health professionals to guide decisions rather than requiring potentially vulnerable people to navigate complex systems in order to provide it themselves. The same principle should be built into plans relating to any qualifying assessment for the new Personal Independence Payment (recommendation 8).

15.2 The Royal College of Psychiatrists and the Department of Health should regularly repeat the National Audit of Schizophrenia on prescribing and make public its results so that not only Mental Health Trusts and providers but also service users and carers can see the performance of local services. Clinical Commissioning Groups should only commission mental health providers who are signed up to the audit and who provide plans for improving practice in response to any outlier results (recommendation 11).

15.3 All Clinical Commissioning Groups commission Early Intervention in Psychosis services with sufficient resources to provide fidelity to the service model. It is crucial that the NHS Commissioning Board holds local commissioners to account for this and we recommend that early intervention services are included in the NHS Commissioning Outcomes Framework (recommendation 22).

15.4 Clinical Commissioning Groups explore the scope to commission integrated community teams bringing together primary care and specialist staff to support people with mental illness in the community (recommendation 30).

15.5 All mental health providers should ensure that people with schizophrenia and psychosis (in hospital and the community) are aware of their right to request a review of their medication including, where appropriate, access to a specialist pharmacist, and are encouraged to exercise it in practice (recommendation 33).

HIV

16. Chronic long-term condition management is becoming increasingly relevant to HIV care. With the continual advances in HIV medicine, the long-term care of patients is now a pertinent and urgent issue for the NHS. Clinicians are now experiencing an increasingly older population of HIV patients who need to be able to maintain their condition on a long-term basis. Care pathways and the management of HIV services need to adapt to cater for this patient cohort, despite the financial pressures of the NHS. Treatment and support must be sustained and enhanced as new structures emerge within an evolving NHS.

17. Janssen broadly supports the recently published BHIVA Standards of Care for People Living with HIV (www.bhiva.org/documents/Standards-of-care/BHIVAStrandsA4.pdf). Specifically for the purposes of this response in relation to LTCs, Janssen endorses BHIVA’s recognition that as people with HIV live longer, their health needs change and both the numbers of co-morbidities and the complexity of prescribing for multiple health conditions increases. BHIVA’s standards (3 and 5) should be referred to by the Health Select Committee to ensure that there is focus on the delivery of high-quality outpatient and inpatient care for HIV services, ensuring that all people have equitable access to high standards of care wherever they live.

18. Monitoring and treatment for people with HIV infection needs to be in accordance with current national guidelines to maximise health and life expectancy and minimise morbidity and mortality. The combination of an ageing HIV cohort, longer duration of HIV infection and long-term antiretroviral therapy for HIV has resulted in a shift in HIV-associated pathology from ill-health associated with severe immunosuppression to non-AIDS co-morbidities such as neurological, heart, liver and renal disease and cancers.

19. Primary care has an important role in the long-term management of HIV. Indeed, due to the increase in non-AIDS comorbidity and the complexity of HIV drug–drug interactions, lack of communication with GPs has been shown to be an important patient safety concern. Establishment of clear protocols and pathways for care between both primary and secondary care is essential for safe delivery of care, and regular communication is strongly recommended unless the patient specifically refuses consent.

Psoriasis

20. For some patients, psoriasis can result in profound functional, psychological, and social morbidity, with consequent reduced levels of employment and income. Factors that contribute to this include symptoms related to the skin (for example, chronic itch, bleeding, scaling and nail involvement), problems related to treatments, psoriatic arthritis, and the effect of living with a highly visible, stigmatising skin disease. Even people with minimal involvement state that psoriasis has a major effect on their life. Several studies have also reported that people with psoriasis, particularly those with severe disease, may be at increased risk of cardiovascular disease, lymphoma and non-melanoma skin cancer.

21. Self care is an essential part of a psoriasis patient’s daily life as well as receiving appropriate support from people involved in their care. While psoriasis can be effectively managed with appropriate treatments, it is essential that patients sustain regular contact with their GP/specialist.

22. Janssen broadly supports the recent Clinical Guideline from NICE on the Management of Psoriasis (http://www.nice.org.uk/nicemedia/live/13938/61190/61190.pdf) particularly the recognition given to the need for psoriasis severity and impact on psychological and social wellbeing to be regularly assessed by the healthcare professional, often in primary care. The need for regular assessments for psoriatic arthritis (PsA) is
also a key priority for implementation, with the guidance recommending that people with psoriasis be assessed for PsA annually, and referred to a Rheumatologist as soon as it is suspected.

23. Janssen also supports the Psoriasis Association’s view that, “Psoriasis is a life-long condition and so patients should be managed effectively and holistically so as to lessen the negative impacts on quality of life and psychological well-being that can be associated with it”.

24. Janssen is committed to ensuring patients with psoriasis lead a life that is as normal as possible. We regularly seek feedback from healthcare professionals and patient organisations to determine what they need. As a result of this two-way dialogue, Janssen believes that key priorities for the management of psoriasis as a long-term condition include:

24.1 Practical support and advice regarding the use of topical therapies:
Many patients currently are expected to just know how to apply their treatments effectively and to get the most satisfactory results from them.

24.2 A review four weeks after starting a new topical treatment in adults: This is standard practice for many long-term conditions to have a follow-up appointment when starting on new treatments and psoriasis should be no different.

24.3 A regular assessment of the impact of psoriasis on the patient:
Patients should be assessed on the impact that psoriasis has on their physical, psychological and social wellbeing and for this impact to be recorded and treated as effectively as the skin manifestation.

9 May 2013

Written evidence from the national Dose Adjustment For Normal Eating programme (LTC 75)

This submission is made on behalf of the national DAFNE programme and as such relates to the provision of structured education for adults with Type 1 diabetes.

Dose Adjustment For Normal Eating (DAFNE) is a skills-based structured education programme in flexible intensive insulin therapy and self-management for adults with type 1 diabetes. On a DAFNE course adults (17+ years) with type 1 diabetes are provided with the knowledge and skills to match their insulin dose to their chosen food intake, enabling them to manage their food choices on a meal by meal basis and in a range of different situations. Specially trained diabetes nurses and dietitians deliver every DAFNE course, which provides 38 hours of structured education to groups of 8 on an outpatient basis over five consecutive days or one day per week for five weeks.

The DAFNE Collaborative comprises all healthcare professionals involved in DAFNE from all of the participating training centres, steered by an elected DAFNE Executive Board. This central DAFNE function provides strategic leadership and direction to DAFNE development, research and implementation. DAFNE is a not for profit hosted within the NHS. The current funding structure relies on financial contributions from all participating diabetes services to sustain the key contributions to quality assurance, peer review and audit.

Provide of the DAFNE programme as a component of diabetes services for people with type 1 diabetes will achieve improved patient outcomes in terms of reduced complications and extended life expectancy with associated cost savings, improved quality of life, and fulfilment of the five NICE standard criteria for structured education.

The DAFNE Collaborative comprises all healthcare professionals involved in DAFNE from all of the participating centres, steered by the elected DAFNE Executive Board. The DAFNE programme is currently funded by annual contributions from all participating diabetes services.

SUMMARY
— The delivery of DAFNE can lead to better integration of primary and secondary care teams.
— There should be dedicated and specific commissioning for adult type 1 diabetes that is separate from services for type 2 diabetes.
— Practical assistance with regard to the commissioning of structured education is available for commissioners.
— Skills based structured education in intensive insulin therapy with an evidence base should be an integral part of the care pathway for type 1 diabetes and not be seen as an optional extra
— Structured education, such as DAFNE, leads to educated and empowered people with type 1 diabetes who are better able to manage their condition.
— Evidence from the DAFNE programme reveals that this training:
  — improves biomedical and psychological outcomes;
  — pays for itself within four—five years due to reduced development of long-term complications;
  — could produce an additional five years life expectancy; and
— is both cost saving and cost effective.

— Provision of structured education for type 1 diabetes which meets the nationally agreed criteria should be centrally funded, mandated and audited.

1. **The Scope of Current Mix of Service Responsibilities so that People are Treated Outside of Hospital.**

1.1 Doctors, diabetes specialist nurses and diabetes dietitians can be trained to deliver DAFNE to people with type 1 diabetes in any location. Traditionally, most type 1 diabetes care is delivered in hospitals, but many DAFNE diabetes teams deliver courses in community and primary care settings, and utilise staff from primary care teams. As such, this bridges the gap between primary and secondary care, and increases knowledge of type1 diabetes and its management within the primary care setting.

2. **The Readiness of Local NHS and Social Care Services to Treat Patients with Long-Term Conditions (Including Multiple Conditions) within the Community**

2.1 Type 1 diabetes is characterised by insulin deficiency that can only be treated with insulin injections. The management issues of type 1 diabetes are very different from type 2 diabetes, and require the input from experienced specialist teams, for example:

— serious and costly medical emergencies due to insulin excess (hypoglycaemia) or deficiency (Diabetic Ketoacidosis—DKA); and

— early age of onset results in long-term disease exposure with resultant complications of eyes, feet and kidneys. Type 1 diabetes costs the NHS £1.9 billion per year, half of which is spent on the treatment of complications.481

2.2 Currently the massive demand for type 2 diabetes services overwhelms the need for specialist type 1 diabetes care and it is neglected. We propose specific and specialised type 1 diabetes care is of paramount importance. The DAFNE Collaborative fully supports the Association of British Clinical Diabetologists (ABCD) “Lost Tribe” campaign for dedicated and specific commissioning for adult type 1 diabetes services in England.482

3. **The Practical Assistance Offered to Commissioners to Support the Design of Services which Promote Community-Based Care and Provide for the Integration of Health and Social Care in the Management of Long-Term Conditions**

3.1 DAFNE have been actively engaged with NHS Diabetes to provide education and support for commissioning of type 1 diabetes services.483 The current payment mechanisms have thwarted primary and secondary care integration. New models of care could be developed, for example, after the provision of the structured education programme by the specialist team the patient can be discharged to primary care but with open access to the specialist team for insulin management support, structured education refreshers and follow-up as part of the care pathway.

3.2 Ultimately, appropriate structured education can result in adults with type 1 diabetes functioning independently in the community, with a reduced requirement for support from healthcare professionals for glycaemic control. This benefits the patient but also the health service by freeing up healthcare professional time to focus on more complex cases.

3.3 Type 1 diabetes is a different disease from type 2 diabetes, with different treatment needs and education requirements. This is not often understood by commissioners. We believe that it is counterproductive for commissioners to be required to “reinvent the wheel” when commissioning for type 1 diabetes services. National programmes which fully meet the required key criteria, such as DAFNE, are available off the peg fully evidence based and priced. We propose that structured education for type 1 diabetes should be commissioned centrally to facilitate commissioning high quality type 1 diabetes care and make it easy for commissioners to avoid the current post code lottery.

4. **The Ability of NHS and Social Care Providers to Treat Multi Morbidities and the Patient as a Person**

4.1 Structured education programmes, such as DAFNE, are designed to educate individuals, taking their own insulin requirement and lifestyle into consideration. Each patient will develop the skills to adjust their insulin dose on a meal by meal basis in a range of situations (eg physical activity and during illness). Goal setting and action planning are integral tools of the course and are reviewed at follow-up. Ultimately DAFNE training provides the individual with knowledge and skills empowering them to control their condition rather than have the condition control them.

481 Hex et al estimating the current and future costs of type 1 and type 2 diabetes in the UK. Diabetic Medicine 2012; 29: 855–56
482 http://www.diabetologists-abcd.org.uk/Type1_Campaign.htm
483 http://www.dafne.uk.com/Why_Structured_Education_-I363.html
5. Implications of an Ageing Population for the Prevalence and Type of Long Term Conditions, together with Evidence about the Extent to which Existing Services will have the Capacity to Meet Further Demand

5.1 People with better controlled type 1 diabetes and an empowered understanding of their condition are less likely to access acute services for complications of their condition and its treatment. Healthy people with diabetes will be economically productive in the workforce, sustaining employment and not accessing income related support due to inability to work.

5.2 Type 1 diabetes costs the NHS £1.9 billion per year, half of which is spent on the treatment of complications. Maintaining good glycaemic control can help prevent or delay the onset of these complications. There is evidence that DAFNE training leads to clinically and statistically significant improved glycaemic control.

5.3 The economic impacts of DAFNE are significant. York Health Economics Consortium published an economic evaluation of DAFNE showing it:

- would save the NHS an estimated £2,237 per patient over 10 years;
- could produce an additional five years life expectancy;
- pays for itself within five years due to reduced rate of development of diabetic complications; and
- is both cost effective and cost saving.

5.4 DAFNE data were considered by NICE as part of the initial consultation for NICE Technology Appraisal60, in which DAFNE is the only programme named as an example of high quality structured education.

5.5 Review of national and local DAFNE service clinical audit data shows:

- severe hypoglycaemia is reduced by 70% and DKA is reduced by more than 60% producing cost savings through reduced paramedic call outs, A&E attendances and hospital admissions.
- restoration of hypoglycaemia awareness in 43% of individuals reporting unawareness pre-DAFNE.
- reduced insulin prescribing costs from a 16% reduction in total insulin use after DAFNE, equating to a saving of £60–£70 per annum for a patient weighing 70kg.

5.6 The economic and audit data from DAFNE have been used to prepare a case study for the Quality, Innovation, Productivity and Prevention (QIPP) collection on the NHS Evidence database. The QIPP case studies are examples of initiatives improving quality and productivity across the NHS and social care. Case studies are evaluated based on quality improvements, savings, evidence and implementation and are peer reviewed. The DAFNE case study:

- shows an estimated £98,133 of real cash savings per 100,000 population achieved through reduced expenditure and improved productivity in healthcare.
- scores within the top 10% of all case studies published in the QIPP collection, and as such is tagged as a recommended publication.

5.7 Hence the provision of DAFNE by specialist diabetes teams can lead to increased life expectancy, whilst reducing NHS costs by the reduction of hypox, DKA and the development of the costly long-term diabetic complications.

6. The Interaction Between Mental Health Conditions and Long-Term Physical Health Conditions

6.1 People with diabetes are more likely to have depression than those without diabetes. The stress of the diagnosis of a long-term condition, the possibility of developing or the development of long-term diabetic complications and not feeling in control can all lead to mental health issues.

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465 DAFNE Study Group. Training in flexible, intensive insulin management to enable dietary freedom in people with type 1 diabetes: dose adjustment for normal eating (DAFNE) randomised controlled trial. BMJ: 2002; 325: 754


6.2 Structured education leads to informed and empowered individuals who feel in control of their diabetes. In addition to the biomedical and economic evidence for DAFNE, there is also evidence of improved psychological outcomes following the completion of the DAFNE course in terms of improved quality of life and psychological wellbeing\(^{488}\) sustained for up to four years post course.\(^{489}\) There is evidence that anxiety and depression also reduce post DAFNE.\(^{490}\)

7. The Extent to Which Patients are Being Offered Personalised Services (Including Evidence of their Contributions to Better Outcomes)

7.1 High quality structured education to enable self-management is the cornerstone of diabetes care. NICE Technical Appraisal 60 recommends that “structured education is made available to all people with diabetes at the time of initial diagnosis and then as required on an ongoing basis, based on formal, regular assessment of need”. DAFNE was uniquely mentioned in the NICE guidance as an example of high quality structured education.

7.2 The provision of structured education that fulfils the nationally agreed criteria from the time of diagnosis, with annual review and access to on-going education, is the first of the 13 quality standards set out in the Diabetes in Adults Quality Standard\(^{493}\) issued in March 2011.

7.3 DAFNE is the only nationally delivered programme for adults with type 1 diabetes which meets the nationally agreed key criteria. It is delivered by 60 specialist diabetes teams (across 138 localities) in England and as of the 29 April 2013, 22,382 adults with type 1 diabetes had completed a DAFNE course.

7.4 Currently there is a huge variation in access to structured type 1 diabetes education across England. We estimate that DAFNE is available in approximately 50% of specialist diabetes services. There is no reliable information to verify what education people with type 1 diabetes are offered. There is a plethora of guidance about structured type 1 diabetes education but a postcode lottery of access to it. We believe that there should be a national minimum standard for type 1 diabetes care that is mandated and audited to drive improvement for this costly and burdensome condition.

9 May 2013

**Written evidence from the British Dermatological Nursing Group (LTC 76)**

The British Dermatological Nursing is a professional membership organisation representing nurses working within dermatology.

**Summary**

— Many dermatological conditions are chronic and can affect the patient both physically and psychologically.

— Dermatology nurses are a key component to a quality patient centred dermatology service.

— Dermatology nursing is primarily practiced in secondary care at present.

— Community based dermatology services need investment to support the development of the nursing component of a multidisciplinary dermatology team.

Many dermatological conditions are long term and the impact of living with these conditions can be devastating both physically and psychologically on the patient. Whilst conditions such as psoriasis and eczema are fairly common in the population, there are many dermatological conditions that are rare and therefore require more specialised care.

Dermatology nurses are a key component to any service. They provide a wide range of treatments as well as running nurse led services providing support and education to patients with common chronic dermatological condition. In many instances, clinical nurse specialists work autonomously providing care and management of patients with chronic dermatological conditions. Many nurses are now non medical prescribers enabling them to diagnose and prescribe a treatment plan in conjunction with the patient. This provides a time efficient service to patients and also frees up consultants time.

Nurses are trained to care for people holistically not just treating a disease or condition. We have the innate ability to work with the patient to determine treatment plans that fit into the patient’s life whilst acknowledging

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\(^{488}\) DAFNE Study Group. Training in flexible, intensive insulin management to enable dietary freedom in people with type 1 diabetes: dose adjustment for normal eating (DAFNE) randomised controlled trial. BMJ. 2002; 325: 754


the patient’s limitations and other constraints on their time. Nurses can often offer longer patient appointment
times in order to undertake patient education and practical demonstration in relation to topical dermatological
treatments. This education and practical support is key to improving adherence to treatment.

Nurses have the ability to build up a rapport with patients and often patients feel more relaxed with nurses
and therefore offer a more realistic account of their condition and treatment. Good communication is a key
skill for any nurse. We are trained to focus our care on the whole patient and can very successfully co-ordinate
care and treatment that fits into the patient’s life outside of the disease.

All nurses should work within their own competence. Building up skills and competence takes time and
supervision. Dermatological care cannot be learnt solely by reading a textbook or attending a course. It also
involves working with expert nurses and consultants clinically to develop the high levels of knowledge, skills
and competency required to practice safely and to provide quality patient outcomes. Peer support is very
important and dermatology nurses rely heavily upon our consultant colleagues to provide this support
particularly in relation to complex or less common conditions.

Our recent workforce survey identified that dermatology nursing is primarily practised in secondary care
with only pockets of dermatology nursing identified in primary care throughout England (1). The British
Dermatological Nursing Group believes that local nursing services in primary care are already overwhelmed
and therefore not in a position to take on the management and care of this large population of patients with
long term dermatological conditions.

Nurses in primary care provide care for a wide range of conditions and therefore do not at present have the
skills and competencies in dermatological care. They cannot be considered experts in a range of conditions.
Furthermore, they cannot be expected to be experts in dermatology if they have never had high level exposure
to the speciality.

Dermatology is not high on the agenda for undergraduate nurse training and many nurses never experience
the speciality during their training. Inpatient dermatology departments were the breeding ground for the many
expert dermatology nurses of today when numerous student nurses had placements within these units. Whilst
we acknowledge that large inpatient departments are no longer cost effective in modern healthcare, we question
how nurses will be able to gain exposure to dermatology when services are fragmented across a range of
healthcare providers.

In times of dermatology service reconfiguration over the years, nurses have been instrumental in service
innovations to continue to provide a quality patient centred service. Day treatment dermatology services and
nursing liaison posts to bridge the gap between primary and secondary care are excellent examples of how
nurses have adapted to this change.

Our main concern is that primary care nursing services are not ready to take on the care of this large group
of patients and that patient care and experience will be compromised if investment is not available to develop
the nursing component of a primary care based dermatology service. The existing primary care nursing
workforce needs exposure to dermatology and the support from employers to do so. Community based service
providers need to build in a robust nursing component into a dermatology service in order to sustain the service
and meet quality standards and guidelines for dermatological treatment and care of patients with skin
conditions. Primary care dermatology services will require audit against these frameworks. Nurses however
should not be viewed as a cheaper alternative to dermatologists but a valuable resource in a multidisciplinary
team.

9 May 2013

REFERENCE

(1) British Dermatological Nursing Group (2013) Dermatology Nursing Services: Results of a National Survey.
Dermatological Nursing, 12 (1) 60—65.

Written evidence from the Association of the British Pharmaceutical Industry (LTC 77)

INTRODUCTION

The ABPI represents innovative research-based biopharmaceutical companies, large, medium and small,
leading an exciting new era of biosciences in the UK.

Our industry, a major contributor to the economy of the UK, brings life-saving and life-enhancing medicines
to patients. Our members supply 90% of all medicines used by the NHS, and are researching and developing
over two-thirds of the current medicines pipeline, ensuring that the UK remains at the forefront of helping
patients prevent and overcome diseases.

The ABPI is recognised by Government as the industry body negotiating on behalf of the branded
pharmaceutical industry, for statutory consultation requirements including the pricing scheme for medicines in
the UK.
The ABPI welcomes the opportunity to submit evidence to the Committee’s inquiry on long term conditions. As the trade association representing companies who develop and supply medicines across a wide range of long term conditions our submission concentrates on the role of medicines and biopharmaceutical companies working in partnership with the NHS across all long term conditions which we hope will be helpful across all the questions the committee is considering.

Already, 15 million people in England have long term conditions, accounting for 70% of health and social care spending and these figures are rising. ABPI welcomes the Government’s commitment to make England one of the best countries in Europe at helping people with long term conditions live healthily and independently. The biopharmaceutical industry also wants to support people with long term conditions to live healthily and independently.

The ABPI welcome the aims outlined in the Department of Health’s “Living Well for Longer: A call to action to reduce avoidable premature mortality” and improving the UKs position relative the other European countries.

It is worth highlighting that significant numbers of people (7.8 million) live with chronic pain and the burden in terms of cost to the NHS is often underestimated. Whilst this is not always recognised in the NHS as a long term condition in itself it frequently coexists with a range of long term conditions.

1. Medicines Optimisation

1.1 Medicines form a key part of the management of long term conditions. Ensuring that that patients gain the maximum benefit from their medicines is crucial both for patient outcomes and the effective use of NHS resources in line with the aims laid out in “The Mandate” (Department of Health November 2012).

1.2 Medicines management, as practiced in the NHS in recent years, has focused on making short term savings by curtailing spend on medicines. The ABPI therefore welcomes NHS England’s focus on medicines optimisation in place of medicines management, and specifically the importance this places on innovation. The ABPI believes that medicines optimisation should focus on improving healthcare outcomes for patients by realising better value from the investment in medicines. For people with long term conditions, who may receive treatment with medicines for all of their lives, the concept of medicines optimisation is particularly relevant.

1.3 The UK spends only 0.9% of GDP on medicines—less than the European average of 1.2%. The percentage of the NHS budget spent on medicines has fallen since 1999—down from 13% to a little under 10%. A focus on cutting the cost of medicines spend through medicines management programmes has already delivered significant savings for the NHS, and continued focus on spend will not be sustainable at this rate without having a detrimental impact on patient outcomes.

1.4 Medicines optimisation is all about having a patient centred approach to medicines use, making sure we improve patient outcomes, reduce wastage, improve safety, increase compliance and realise the full value of medicines as a consequence. Correctly used, medicines have the potential to:

— Improve outcomes and the quality of life for patients.
— Prevent expensive healthcare interventions such as additional healthcare professional visits and unplanned hospitalisations.
— Prevent costly progression of disease.
— Enable the redesign of pathways of care to extract maximum value from the medicine and the local health and social care resources.
— Reduce adverse events, waste and errors that cost the local health economy a significant amount each year and adversely affect patients’ lives.
— Improve patients’ adherence to treatment regimes.

1.5. The ABPI believes that medicines optimisation should rightly focus on medicines safety, adherence and reducing wastage, and also ensure that the intrinsic value of medicines in improving healthcare outcomes for patients is realised. Medicines optimisation is the key to ensuring the right patients get the right medicine, at the right time and in turn improving adherence, reducing waste and eliminating harm due to inappropriate medicines use or prescribing.

1.6. The ABPI supports the Royal Pharmaceutical Society’s four guiding principles for medicines optimisation:

— Aim to understand the patient’s experience.
— Evidence based choice of medicines.
— Ensure medicines use is as safe as possible.
— Make medicines optimisation part of routine practice.

1.7. The ABPI recommends that a whole system approach is taken on medicines optimisation. Community pharmacy should have a prominent role in delivering the medicines optimisation agenda, and all relevant organisations should adopt national medicines optimisation policies.
1.8. The ABPI recommends that local implementation metrics reflect the national medicines optimisation agenda. The ABPI further recommends that clear support and guidance is offered on a national level on how medicines optimisation can be implemented and delivered locally.

2. **Case Study: Medicines Optimisation and Atrial Fibrillation**

2.1 The case of study below demonstrates how innovative medicines can significantly improve and change a patient pathway.

2.2 Atrial fibrillation (AF) is the most common sustained heart arrhythmia and is characterised by an erratic and often rapid heart rhythm. This long term condition is estimated to affect in excess of one million people in the UK, with 200,000 patients being newly diagnosed each year. With an ageing population, the AF population is set to double in the next forty years. AF is a major cause of stroke, meaning that Patients with AF can often be a "walking time bomb" unless they receive appropriate and well-managed anticoagulation. It is estimated that 12,500 strokes are directly attributable to AF each year. The prevalence of AF increases rapidly with age as the incidence of resulting strokes rises from 1.5% among people ages 50–59 to 23.5% among people aged 80–89.

2.3 It is estimated that stroke care costs the NHS £2.2 billion in direct care costs and costs the wider economy an additional £1.8 billion in loss of productivity and disability. Indirect care costs, such as home nursing, are estimated to be £2.4 billion. Annually, stroke patients occupy up to a quarter of total hospital bed days. Given the increased severity of AF-related strokes and the fact that AF-related stroke patients have longer hospital stays than other stroke patients, AF-related strokes are costly to the NHS to manage—the cost per stroke due to AF is estimated to be £11,900 in the first year after stroke occurrence.

2.4 AF-related stroke can be prevented through anticoagulation. Historically the only anticoagulant available has been warfarin. Patients receiving warfarin need to have their INR frequently monitored. This generally represents a trip to hospital, GP or a pharmacy-led clinic every two—four weeks, and poses significant time burden on people with AF. The estimated costs for a visit to an anticoagulation clinic are £17 for the first appointment and £18 for each subsequent visit.

2.5 The Novel Oral AntiCoagulants (NOACs) mean that whilst patients require some monitoring they require significantly fewer visits to hospitals. The NOACs have been approved by NICE for the prevention of AF-related stroke as clinically effective for use on the NHS.

2.6 Evidence suggests that commissioners at the local NHS level are slow to implement the NICE guidance which recommends NOACs for use in the NHS. There is anecdotal evidence that this is due to concerns about the higher prescribing cost associated with these newer treatments when compared to the cost of warfarin.

2.7 While the daily cost of NOACs is certainly higher than the daily cost of warfarin, warfarin prescribing costs cannot be disassociated from the infrastructure costs of the anticoagulation clinics required for INR monitoring. The additional infrastructure costs for warfarin—not required for NOACs—adds significantly to the true cost of using warfarin, and therefore reduces the overall cost difference between warfarin and NOACs. Also the NOACs have additional clinical and practical advantages over warfarin which could lead to fewer clinical events. This was recognised in the recent “Catalogue of Potential Innovations” published by the Department of Health in March 2013. Service improvement leads are encouraged to take up the innovations in this publication.

2.8 Despite NICE guidance recommending NOACs as cost effective treatment options to be considered alongside warfarin, uptake of the medicines, and the innovation they bring, has been slow in some parts of the country due to restrictions at a local level in terms of formularies, local protocols and pathways. This suggests a focus on short term cost savings that can be associated with the medicines management approach outlined above. A medicines optimisation approach, with better outcomes for patients at its centre, would suggest that the improved outcomes and long term value for money would make an investment in NOAC treatment worthwhile.

2.9 Whilst the Government’s recently published National Cardiovascular Disease Outcomes Strategy, which mentions AF is to be welcomed, it contains no recommendations for NHS policy interventions to incentivise improvement detection, management and treatment of AF to achieve stroke prevention and associated mortality reduction.

3. **Joint Working**

3.1 Pharmaceutical companies can improve the care for patients with long term condition by Joint Working programmes with the NHS.

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494 “Progress in Improving Stroke Care”, February 2010, National Audit Office
3.2 Joint working is where pharmaceutical companies pool skills, experience and/or resources with the NHS for the joint development and implementation of patient-centred projects. All joint working projects are carried out expressly and primarily for the benefit of patients. Joint working has already benefited thousands of patients across the UK with projects assisting in the reduction of COPD admissions, improvements in vascular checkups and improved outcomes for diabetes patients.

3.3 The pharmaceutical industry has considerable commercial experience and management expertise that can be brought to joint working projects. Companies also have valuable experience and knowledge of the disease areas for which they provide treatments. It is important that the NHS is able to access these resources as a spur for innovation in caring for people with long term conditions, and that successful innovations are spread throughout the NHS.

3.4 Examples of successful joint working include a project in Nottingham to reduce COPD exacerbations. A clinical audit and treatment review of all Nottingham City patients admitted to Nottingham University Hospitals NHS Trust with an exacerbation of their COPD was carried out and analysis of the data enabled identification of whether care prior to admission had been managed according to the NICE clinical guideline. It also enabled identification of areas of potential improvement in local care pathways and treatment guidelines. Service changes now include: development and implementation of a personalised self management plan for all patients with COPD; treatment reviews of all patients with COPD who have had one or more exacerbations in the previous 12 months to ensure they are being managed in line with NICE guidelines using four respiratory nurse specialists seconded to the programme from company partners; development and implementation of a bespoke COPD clinical management template for GP clinical systems; primary care professional training and education.

3.5 In Haringey, an innovative, long term conditions pilot programme was launched in 2004 to provide person-centred, telephone-based support for 600 patients with diabetes, heart failure and coronary heart disease by supporting them to take a more informed and active role in their healthcare. A team of dedicated care managers, all of whom were qualified nurses, provided assessment, care planning, regular coaching and support for patients based on their individual needs, signposting them to other services as appropriate. They used decision support software to facilitate proactive communication with patients, and which also provided and recorded information for ongoing care management. The expectation of the programme was that, through regular communication, patients would become more successful in managing their condition and improve their clinical outcomes and quality of life, while reducing the demands on local health services.

Written evidence from the Health Foundation (LTC 78)

1.0 EXECUTIVE SUMMARY

1.1 The Health Foundation is an independent charity working to improve the quality of healthcare in the UK. Informed by our research and improvement programmes, this submission of evidence considers the ability of the NHS to “treat the patient as a person” and recommends changes needed to deliver high quality, person-centred care for people with long-term conditions.

1.2 The NHS has only a very limited ability to deliver person-centred care for people with long-term conditions. This is because patients are largely viewed by clinicians as passive recipients of care and few are supported to develop the skills, confidence and behaviour to effectively manage their conditions. Furthermore, the way that the health system is structured and its processes are organised poses a barrier to more person-centred care.

1.3 The vast majority of care for a person with long-term conditions is delivered by the individual patient themselves because they are living with their condition every day. It is therefore essential that improvement of health services is focused upon supporting people to effectively manage their own conditions.

1.4 There must be changes to the roles, mindsets and behaviours of patients and clinicians, supported by processes and infrastructure that enable a new relationship of partnership between people and health professionals.

1.5 To make the rhetoric of person-centred care a reality, action is required by clinical commissioning groups, NHS England and those bodies with influence on the education and training of health professionals.

2.0 WHAT IS PERSON-CENTRED CARE AND WHY IS IT IMPORTANT?

2.1 Coordinated, community-based services are important, but not on their own sufficient, to deliver sustainable and effective care for people with long-term conditions. There needs to be a fundamental change in how government and the NHS think about care for people with long-term conditions.

2.2 It is vital that the improvement of long-term conditions management is focused on the role patients themselves can play in effectively managing their conditions. On average, a person with a long-term condition
spends just three hours each year in contact with a health professional, and that contact does not always coincide with the periods of time when an individual most needs support.

2.3 Person-centred care should support people to self-manage, offer personalised care planning and enable people to share in decision making. It should use the limited time patients spend with a health professional to: enable patients to become knowledgeable, confident managers of their health; support people with long-term conditions to make informed decisions about and to successfully manage their own, health and care; deliver care that is responsive to people’s individual abilities, preferences, lifestyles and goals.

2.4 Despite the promotion of these approaches by government and health policy leaders, truly person-centred care has not spread beyond core innovators. The ability of the NHS to “treat the patient as a person” is far too limited.

2.5 Creating this person-centred health system requires different roles, behaviours and mindsets from clinicians and patients, supported by processes and infrastructure that enable new relationships. Health professionals need to view people as partners in their care, rather than passive recipients. They need to understand the motivations and challenges that each individual faces in adopting healthy behaviours—not just the biomedical challenges, but psychological and social challenges as well.

2.6 This requires a fundamental shift in how health services are delivered, with the emphasis moving from focusing on improving clinical outcomes to quality of life, from providing specialist treatment to generic support, and from a system that reacts to people’s ill health to one that focuses proactively on enabling people to live as healthily as possible.

3.0 OUR EVIDENCE BASE

3.1 This submission of evidence is informed by the Health Foundation’s improvement programmes and research, and focuses primarily upon our learning about how to effectively implement self management support and shared decision making.

3.2 Starting in 2007, the Health Foundation’s Co-creating Health (CCH) improvement programme worked for five years with several NHS sites to demonstrate the best ways to redesign routine care so that patients are well supported to manage their long-term conditions. It featured training programmes for patients and health professionals and a service improvement programme. Four sites have now been given additional funding which they will be using over the next two years to continue to embed self management in their services.

3.3 The Health Foundation’s Making Good Decisions in Collaboration (MAGIC) improvement programme has been exploring how clinical services can support patients to share in decision making. MAGIC has not been tested specifically in the context of long-term conditions, but is relevant because people with long-term conditions are faced with care and treatment options.

3.4 Our Closing the Gap through Changing Relationships and Shine improvement programmes have supported NHS teams to explore innovative ways to improving care. Projects have included the provision of home-based web consultations for patients with diabetes and support for people with kidney disease to use self-dialysis in hospital.

3.5 The research we draw on in this submission includes our syntheses of the evidence bases for self-management support and shared decision making and an exploration of the interaction between patients and clinicians during the consultation.

4.0 BARRIERS TO PERSON-CENTRED CARE

4.1 The barriers to person-centred care are largely cultural and arise from the three key participants in healthcare: health professionals, patients and organisational processes.

4.2 Health professionals.

The attitudes, beliefs and behaviours ingrained in health professionals limit their ability to provide effective, person-centred care. Barriers include the following:

4.2.1 “We already do that.” There is a lack of a clear, shared understanding about what effective person-centred care looks like. When urged to participate in our programmes, many health professionals said they already are supporting their patients to self-manage or are using shared decision making.

499 Further information about self management support and shared decision making is available on the Health Foundation’s resource centres at http://selfmanagementsupport.health.org.uk/ and http://shareddecisionmaking.health.org.uk/.

499 Further information about CCH is available at http://www.health.org.uk/areas-of-work/programmes/co-creating-health/.

500 Further information about MAGIC is available at http://www.health.org.uk/areas-of-work/programmes/shared-decision-making/.


502 Further information about Shine is available at http://www.health.org.uk/areas-of-work/programmes/shine-eleven/.


But after training sessions, many realised that they had not been using a truly person-centred approach.

4.2.2 “There isn’t enough time.” A common response to our programmes was that health professionals felt they had too much to do and no time to participate in training or to engage in self-management support and shared decision making. Clinicians also feared that the approaches would lengthen the time of consultations.

4.2.3 Health professionals lack understanding about the value of involving patients in design and delivery. In Co-creating Health, for example, lay tutors sometimes found that health professionals questioned the role patients could play in clinician training.

4.2.4 Health professionals are not taught skills necessary for person-centred support. Our programmes found that few health professionals are equipped with the knowledge and skills necessary to understand what motivates their patients and support them to change behaviours.

4.3 Patients

Individuals with long-term conditions may have a poorer quality of life, lower levels of support from social networks, and less confidence in their ability to manage their health than people without long-term conditions. Barriers include the following:

4.3.1 Patients lack of knowledge, skills, and confidence to effectively manage their own health. Being diagnosed with a long-term condition is a life-changing event which may involve changes in lifestyle and require new competencies in, for example, medicines management.

4.3.2 Patients feel “doctor knows best”. Feelings of deference or anxiety towards health professionals made some patients reluctant to engage in training programmes or in a new kind of consultation in which they act as partners with clinicians in planning and making decisions about their care.

4.4 Organisational processes

Healthcare delivery systems—including the services that are commissioned, operational systems and financial incentives—can be barriers to person-centred care. These barriers include the following:

4.4.1 Patients lack access to a range of services that fit their individual needs and abilities. Providing information alone is not enough to support people with long-term conditions. People need proactive support to help them develop the confidence, skills and knowledge to manage their health and care.

4.4.2 Commissioners lack an understanding of person-centred care and “how to get it”. Commissioners who gave insights for Co-creating Health recognised the role of self-management support in reducing pressure on services. However, their understanding of effective self-management support was mixed and some were unsure about how to commission it.

4.4.3 IT systems can prevent easy access and flow of information. For example, one Co-creating Health team faced the problem of GPs using different IT systems, which prevented them from flagging patients participating in the training programme.

4.4.4 Lack of access to test results or other information in advance of a consultation. Our systems are designed to give test results or information about treatment options during the consultation, which hinders agenda setting, care planning and shared decision making within allotted consultation times.

4.4.5 Tariffs are not always aligned to provide self-management support. In our shared haemodialysis project, for example, people with kidney disease learnt to self-administer dialysis in hospital, gaining independence and freeing up staff. Patients use button holing—a means to self-administer dialysis—but the tariff acts as a disincentive because the needles necessary are more expensive than the sharper needles used in staff-administered dialysis.

5.0 What we have learned about how to overcome these barriers

5.1 Creating a culture that supports person-centred care is a significant challenge. Our programme teams have had to be creative and flexible to overcome barriers. Support from senior leadership—up to trust board levels—has been vital in gaining traction.

5.2 Changing culture and behaviours among health professionals

Health professionals need education, training, and development that gives them the knowledge and skills required for person-centred care. The Health Foundation has learnt the importance of the following:

5.2.1 Encouraging participation in training. Getting health professionals to participate in training required clearly setting out the benefits of self-management support and shared decision making. To address time concerns, teams had to adapt training, in some cases shortening the programme or offering...

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mini-training sessions to support staff. Those who participated found that using shared decision making and agenda setting helped to structure consultations.

5.2.2 Training whole teams. Co-creating Health found it important to train whole teams of health professionals from the same service, so that everyone involved had a common understanding of self-management support and its tools and techniques.

5.2.3 Ensuring health professionals have the right skills. Training involved role playing as well as education in support techniques such as motivational interviewing and coaching skills, which are key to helping patients build confidence.

5.3 Changing culture and behaviours among patients
Patients who attended Co-creating Health group sessions had, on average, become more motivated and confident to self-manage.

5.3.1 Encouraging participation in patient training. Co-creating Health found that patients sometimes needed encouragement from a trusted source—especially their GP—to prompt them to participate in a training programme.

5.3.2 Offering activities that build confidence. Co-creating Health offered biomedical, psychological and in some cases social support through peer support. Group sessions included goal setting, problem solving, and relaxation, as well as condition-specific training such as self-monitoring or managing pain. Lay and clinical tutors used techniques such as positive psychology, motivational interviewing and helping people identify unhelpful beliefs.

5.3.3 Adapting to patients’ needs and preferences. Teams sometimes changed the length or content of sessions to suit patients. They developed creative ways to promote and carry out self-management support, such as through practice-based resource libraries or text messages to follow up on goals.

5.3.4 Involving patients in design and delivery of training sessions. Several project managers found that involving patients in the design, development and implementation of the programmes was vital to meet patients’ needs because the patient perspective “could not be imagined” by professionals.

5.3.5 Promoting peer support. Peer support at some sites also helped motivate people to engage. Peer support activities ranged from regular phone calls with a “buddy”, reunions for those who had participated in training together, and a peer-led walking group.

5.4 Changing systems
Whole system change is needed to integrate person-centred care into care pathways. More work is needed at all levels to investigate and consider what systems or tariffs are supporting or hampering person-centred care. Our programme teams made some progress in this with help from their wider organisations. Progress included the following:

5.4.1 Developing tools and support for clinicians. Some teams developed agenda-setting sheets to help patients identify what they want from a consultation, confidence rulers to help assess the likelihood of a behaviour change and health plans to capture patients’ commitments to their actions. Other teams developed electronic templates to prompt clinicians and help structure consultations. Administrative staff members were trained to help get information out before consultations.

5.4.2 Creating access to home-based solutions that promote independence. A Health Foundation project has offered diabetes follow-up consultations by web-cam. Patients reported that, compared to face-to-face appointments, web consultations saved time, were more convenient and that they would be more likely to attend them.

6.0 Recommendations
We want to see as many people as possible supported to develop the skills, knowledge and confidence to successfully manage their health. To make this possible:

— commissioners should prioritise their duty to promote involvement of patients in their care and treatment, including by involving people with long-term conditions in designing and developing support services and making sure they have access to a wide menu of options providing tailored support such as training programmes and peer support;

— NHS England should support clinical commissioning groups to commission services that support self-management by sharing best practice;

— NHS England, working with Monitor, should ensure financial incentives encourage and support self management, and do not obstruct it;

509 Programme evaluators used the Patient Activation Measure, a licensed tool for evaluating a patient’s level of knowledge, skills and confidence to self-manage.

510 Further information about this project is available at http://www.health.org.uk/areas-of-work/programmes/shine-eleven/related-projects/newham-university-hospital/
— NHS England should use the available measures to assess how well people are being supported to self manage and to invest in developing these measures further; and
— Health Education England, royal colleges and professional regulators should bring person-centred care principles and training into undergraduate, postgraduate and continuing professional education curricula.

7.0 Oral Evidence

The Health Foundation would be pleased to give oral evidence to the committee if it would be helpful to the inquiry.

9 May 2013

Written evidence from Stroke Association (LTC 79)

KEY POINTS
— Stroke is the third biggest killer and the largest single cause of severe adult disability in the UK. There are around 111,000 strokes and 20,000 Transient Ischaemic Attacks (TIA or “mini strokes”) in England a year and over 300,000 people are living with moderate to severe disability as a result of stroke.
— Stroke is also one of the most expensive conditions, with direct care costs to the NHS of £3 billion every single year, within a wider economic cost of £8 billion.
— Progress reports on stroke care from the National Audit Office (NAO) in 2010 and the Care Quality Commission (CQC) 2011 review of life after stroke support conclude that the improvements in acute care for stroke are not yet being matched in post-hospital and longer term support.
— Stroke survivors and carers often describe their interactions with the health and social care system as confused and poorly coordinated.
— There are significant problems with stroke survivors’ access to effective needs assessment and care planning.
— All stroke survivors should be able to access a named person to co-ordinate their health and social care needs. This is currently not the case.
— Survivors report access to therapies as too brief to enable best possible longer term recovery.
— More work must be done for Cardiovascular Diseases to be managed as a single family of diseases to help improve care for people with multiple Cardiovascular morbidities.

1. THE BURDEN OF CARDIOVASCULAR DISEASE

1.1 Cardiovascular disease (CVD) is a common condition caused by atherosclerosis (furring or stiffening of the arteries). CVD (including conditions such as stroke, coronary heart disease, diabetes and chronic kidney disease) was responsible for nearly 30% of deaths in 2011—and is the largest cause of disability.

1.2 Major improvements have been made in the prevention and treatment of CVD over the last decade, with a 40% reduction in under 75 mortality rates for all CVD conditions and a 42% reduction in under 75 mortality for stroke.

1.3 Despite these improvements, future demographic shifts (in particular levels of obesity and an ageing population) threaten the gains that have been made. By 2022 the number of people at more than 20% risk of CVD could rise from 3.5 million in 2010 to 4.2 million.511

2. CVD COMMON RISK FACTORS AND MULTI-MORBIDITIES

2.1 CVD in practice represents a single family of diseases linked by common risk factors.

2.2 Many people who have one CVD condition commonly suffer from another and the existence of one condition can create excess risk of developing others. For example patients with diabetes have a 25% excess risk rate for stroke and a 65% excess risk rate of heart failure.

2.3 Currently patients with multi CVD morbidities often receive care both in hospitals and the community from multiple different teams in a disjointed way.

2.4 The Department of Health’s Cardiovascular Disease Outcomes Strategy (March 2013) focuses on ways that CVD can be managed as a single family of diseases and considers how a more co-ordinated approach is needed to assessment, treatment and care to improve outcomes for patients.

3. Coordinated and Patient Centred Long Term Care for Stroke Survivors

3.1 People who have had a stroke and their carers need to be able to access a range of services after they have been transferred home. Many will need further community based rehabilitation, such as physiotherapy, speech and language therapy or occupational therapy. Many stroke survivors and carers also need broader support to help them manage life after stroke.

3.2 Progress reports on stroke care from the NAO in 2010 and the 2011 CQC review conclude that the improvements in acute care for stroke are not yet being matched in post-hospital and longer term support. The CQC also found wide levels of variation both between and within different areas in the accessibility and quality of care and support provided to people following transfer home. These findings were backed up by the Stroke Association’s 2012 Daily Life Survey of over 2,200 stroke survivors and carers.

3.3 Stroke survivors and carers often describe their interactions with the health and social care system as confused and poorly coordinated. Typical problems include dealing with a range of different care professionals who have not shared information about them, appointments and visits that are poorly scheduled, patients feeling that they lack information and do not know who to contact for advice and support, as well as unnecessary repeat tests and failure to organise adequate community based support after patients leave hospital.

4. Assessment and Care Planning

4.1 Health and social care needs assessments are the gateway to stroke survivors getting the right support and services. These assessments should be then turned into a written care plan encompassing health, social and preventative care.

4.2 The Daily Life survey found that 39% of respondents had not been offered an assessment for their health and social care needs beyond hospital. Of those who had received an assessment of their needs, 60% of people had not received a care plan.

4.3 According to best practice stroke survivors should also be offered a review of their health social care and secondary prevention needs within six weeks of leaving hospital, six months on and then annually. This is because people’s condition and support needs can change.

4.4 The CQC review showed while most PCT areas have systems for reviews after 6 weeks, systems for reviews after this are in place in less than a quarter of areas. This finding was supported by the Daily Life Survey which found that in England 47% of respondents who had received a review had only had one review. The CQC also found that only 34% of areas had a framework for joint reviews of people’s health and social care needs.

4.5 Local projects have demonstrated that effective review processes can deliver a range of benefits, including reducing emergency readmissions, improving secondary prevention and providing better support for stroke survivors and their carers.

4.6 Following a successful pilot in partnership with Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for Greater Manchester, 15 Stroke Association Information, Advice and Support (IAS) services across England are now already delivering six month post-stroke reviews.

4.7 It is also vital that carers for stroke survivors are made aware of their own right to an assessment of their needs. However, the Daily Life Survey found that 40% of respondents with a carer said their carer had not received and assessment because they were unaware they had a right to one.

4.8 Stroke survivors, along with all patients and carers with a long term condition, should also be offered the opportunity and relevant information to help them develop a personalised self-management plan which is integrated into the formal care planning process.

5. Support for Joined up Health and Social Care

5.1 Effective communication between health and social care teams is one of the most important aspects of stroke care.

5.2 When health and social care don’t work well together, the result is a worse experience and this was the situation described by 48% of English respondents to the Daily Life Survey.

5.3 Through the survey we heard of missed appointments, meetings cancelled at the last minute and administrative errors resulting in survivors not getting the support they needed. This left them and their families feeling as though they were seen purely as a series of health conditions rather than as people, keen to be supported to make their best possible recovery.

5.4 To help improve the experience people have and ensure that care plans are effectively implemented across health and social care, all stroke survivors should be able to access a named person to co-ordinate their

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health and social care needs. Each year, the Stroke Association provides such support to over 35,000 people affected by stroke, through our Communication and Advice, Information and Support services.

5.5 The CQC review found significant variation in the proportion of stroke survivors who are given access to a named coordinator and also variation in the services that they cover. Only 54% of PCT areas provided people with a single contact who looks across health, social and community services. In less than half of areas this support covered services such as community transport, access to leisure facilities or finding training and voluntary activities. These contacts could coordinate across different services (e.g., ensuring all appointments are on the same day) in only 40% of areas.

5.6 By widening access to stroke coordinators, not only can we achieve better outcomes for individuals but also begin to tackle the lack of understanding among health and social care professionals of stroke and its impact, and the problems this causes.

6. Early Supported Discharge for Stroke

6.1 Early Supported Discharge services provide a greater proportion of early rehabilitation for stroke survivors in the community rather than in hospital. Although not suitable for everyone, it is estimated that around 40% of patients could benefit from ESD. Research has shown that ESD can achieve better outcomes for patients as well as relieving the demand on beds in stroke units and bringing down costs for the hospitals running the service by around £500 per patient.\(^5\)\(^15\)

6.2 Currently only 45% of stroke units offer ESD and only around 20% of stroke patients benefit from the service. However, if this was raised to the optimal level of 40% there could be approximately 900 fewer cases of death and disability each year in England.\(^5\)\(^16\)

7. Access to Therapies and Support Services

7.1 Survivors report access to therapies as too brief to enable best possible recoveries despite the National Stroke Strategy stating that stroke specialisation rehabilitation should be available for as long as it continues to be of benefit. The 2011 CQC review found particular problems with availability of stroke specialist physiotherapy and significant delays in accessing speech and language therapy.

7.2 The emotional impact of stroke can be just as devastating as the physical effects. The Stroke Association’s Feeling Overwhelmed report\(^5\)\(^17\) found that 67% of stroke survivors had experienced anxiety and 59% felt depressed. Healthcare costs for people with long-term conditions who also have depression are typically 45% higher than those without.\(^5\)\(^18\) Depression is also associated with a fourfold increase in the risk of cardiovascular disease.

7.3 Despite this need the CQC review found that less than 40% of PCT areas provided good access to psychological therapy or support from stroke councillors.

7.4 The Feeling Overwhelmed report also found that only two in ten stroke survivors were given information, advice and support on coping with the emotional aspects of stroke and almost two thirds agreed or strongly agreed that their emotional needs were not looked after as much as their physical needs.

7.5 Along with the need for specialist community-based rehabilitation and therapies stroke survivors and carers also frequently talk of the need for more longer-term support for managing life after stroke.

7.6 The CQC found that people particularly valued the help and support provided by other people who had experience of stroke. Most PCTs reported that peer-support groups (usually run or supported by voluntary sector organisations such as the Stroke Association) were available in at least part of the area they cover, but only 60% reported they were available to everyone. Access to specific peer support for people with aphasia (communication disability following stroke), for people of working age or for people in care homes, was more limited.

8. Access to Information

8.1 Stroke survivors, their carers and families need the right information, provided at the right time and in the right form to have the maximum chance of accessing support and living well following a stroke.

8.2 The CQC found that most of the information packs provided by PCTs to people when they were transferred home after a stroke were judged to have good information on reducing the risks of stroke, and on services for carers. However, only 40% of these packs contained good information on local services, and even fewer had good information on money or benefits and making complaints. Only 40% of areas gave people information

516 Department of Health (2013) Cardiovascular Disease Outcomes Strategy
on why and when services will end and 29% of social service departments were found to not give people information about how to ask for a re-assessment of their needs.

8.3 Direct payments and individual budgets have the potential to help some stroke survivors personalise their social care and other services to meet their needs. However, take up remains low and the CQC propose that this could be as a result of only 31% of PCT areas giving people who have had a stroke written information about them when they have left hospital.

8.4 The voluntary sector can also play an important role in providing expert and accessible information to stroke survivors, carers and professionals. The Stroke Association operates an information service, helpline and website and produces a comprehensive range of written materials in a variety of languages and formats.

8.5 A number of health and social care services around England make good use of voluntary sector resources and in some cases directly commission voluntary sector information and support services. However many people who have had a stroke and their carers are not being made aware of the free sources of advice available to them. The Daily Life Survey showed that nearly 30% of respondents in England were unaware of such free sources of care and support.

8.6 Many stroke survivors would also value better access to information about their own care and medical records. As discussed earlier too few stroke survivors are even given a copy of their own care plan let alone further information about their treatment and on-going care.

9. Involving Stroke Survivors to Help Design Services

9.1 We believe that by involving stroke survivors, health and social care services will be better designed and avoid many of the pitfalls that are all too familiar to those that use them.

9.2 The CQC looked at the broader involvement of people who have had a stroke and their carers in decisions about the design and delivery of services. All PCT areas had carried out such work, linked to the implementation of the National Stroke Strategy, most often through surveys and focus groups. However, this work may not have always included some of the main groups affected by stroke. 9.3 For example, only 65% of areas have done specific involvement work with people with aphasia, only a third have targeted people who live alone, and only 17% have targeted people in care homes.

9.4 The CQC also found that some services could do more to encourage people to engage more in the day-to-day running of services. Only around a third of information packs explained how to complain about stroke services, or to make suggestions for how they could improve.

9 May 2013

Written evidence from Men’s Health Expert Policy Group (LTC 80)

The Men’s Health Expert Policy Group is a multi-disciplinary group of leading primary and secondary care clinicians, charities and advocacy groups with specialist interests in men’s health, endocrinology, cardiovascular disease, and sexual health.

The Group would like to take this opportunity to respond to the Health Select Committee’s inquiry examining how the NHS in England can improve the care for people with long-term conditions, particularly people suffering from diabetes. There is strong evidence of the links between common men’s health problems, such as erectile dysfunction (ED) and testosterone deficiency syndrome (TDS), and more serious long-term conditions such as type-2 diabetes. It is important therefore that the Committee considers these as part of its inquiry. Our recommendations to the Committee are in bold.

As the Committee will be aware, ED is the consistent inability to get or maintain an erection during sexual intercourse and is thought to affect more than one in ten men.\textsuperscript{519} On the other hand, TDS is estimated to affect one in ten men between the ages of 20 and 79\textsuperscript{520} and is a condition where the body does not produce enough of the hormone testosterone. Although both conditions can be treated, there is significant variation in the quality of services being provided and commissioned for these conditions in England,\textsuperscript{521} which can result in missed diagnosis and failure to treat.

In March 2013, the Department of Health published its sexual health policy document, \textit{A Framework for Sexual Health Improvement in England}, and the accompanying commissioning guidance for local authorities, \textit{Commissioning Sexual Health Services and Interventions: Best Practice Guidance for Local Authorities}.

The Framework recognises that erectile dysfunction (ED) is “a marker for underlying CVD [cardiovascular disease] and health professionals should be alert to this issue, which provides an early opportunity to treat the risks of CVD as well as addressing erectile dysfunction”\textsuperscript{521}. The Group welcomes this inclusion within the Framework as an acknowledgement of the growing body of evidence to demonstrate that common men’s health

\textsuperscript{519} Sexual Advice Association, \textit{Impotence or erectile dysfunction}, October 2011
\textsuperscript{520} Haring et.al. The Aging Male, December 2010; 13(4): 247–257
\textsuperscript{521} Paul Uppal MP, \textit{The State of Half the Nation: Diagnosing heart disease and Type 2 diabetes earlier in men}, December 2012
conditions can be indicators of an elevated risk of developing more serious cardiovascular conditions—
including type-2 diabetes.

However, despite recognition of this, both the Framework and the subsequent guidance fail to provide clarity
about where responsibilities lie for the commissioning of men’s health services. This is with the exception of
vasectomy. The documents also provide no information about how the commissioning of specific men’s health
services, including for managing ED and TDS, will be shared between local authorities, clinical commissioning
groups (CCGs) and NHS England.

Given the linkages between men’s health conditions and more serious long-term conditions, the Committee
should recommend that the Department of Health, with NHS England and Public Health England, provide
further clarity about where responsibility for men’s health sits to ensure patients have a joined-up experience
of care and promote earlier diagnosis.

Early complications of type 2 diabetes include ED and TDS, and can often be identified before a man is
given a diagnosis of the condition. For example, by the time people with type 2 diabetes are diagnosed, it is
estimated that half are already showing signs of complications of their disease which, for men, could include
erectile problems. Furthermore, it has been estimated that complications may appear five to six years before
they have a diagnosis of the underlying disease.

The Committee should recommend that government, the NHS and healthcare professionals consider ED and
TDS as an important warning sign for diabetes before more serious complications arise. Furthermore, it is
important that GPs ask men with diabetes about ED as this is a serious consequence of the condition and can
also be a symptom of TDS.

The National Institute for Health and Care Excellence (NICE) clinical guideline for the management of type
2 diabetes identifies ED as a side-effect of diabetes in men. The guideline outlines that clinicians should:

— Review the issue of ED with men annually.
— Provide assessment and education for men with ED to address contributory factors and treatment
  options.
— Offer a phosphodiesterase-5 inhibitor (choosing the drug with the lowest acquisition cost), in the
  absence of contraindications if ED is a problem.
— Following discussion, refer to a service offering other medical, surgical, or psychological
  management of ED if phosphodiesterase-5 inhibitors have been unsuccessful.

It is important that healthcare professionals follow these guidelines and local health bodies monitor its
implementation.

Building on this guidance, the Group has welcomed the inclusion of two new indicators to the Quality
Outcomes Framework for 2013–14 of relevance to ED and diabetes. These indicators are aimed at incentivising GPs to ask male patients with diabetes about ED and the treatment options for ED. The inclusion
of these indicators represents an important step in ensuring men’s health issues are appropriately prioritised in
primary care.

However, with one in five GPs admitting that they are not comfortable talking to men about sexual health
issues, further support needs to be made available to ensure primary care practitioners have the training and
resources to discuss these important issues, and that men are having equal access to the care and support they
need. The Committee should recommend that Public Health England work with the Royal College of General
Practitioners to take this agenda forward as part of the wider Making every contact count initiative.

Furthermore, the Cardiovascular Disease Outcomes Strategy commits NHS England to work with
stakeholders “to identify how to incentivise and support primary care consistently to provide good management
of people with or at risk of CVD”, including from relevant QOF indicators. The Group supports this
commitment. The Committee should recommend that, as part of this work, NHS England looks at how the QOF
indicators for ED and diabetes are being implemented and identifies areas where these can be improved upon.

MEMBERS OF THE MEN’S HEALTH EXPERT POLICY GROUP

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522 Diabetes UK, Diabetes in the UK 2012: Key statistics on diabetes, April 2012
523 Harris MI, Klein R, Welborn TA et al (1992), Onset of NIDDM occurs at least 4–7 years before clinical diagnosis, Diabetes Care 15 (7); 815–819
524 NICE, CG87—Type 2 diabetes: The management of type 2 diabetes, May 2009
526 ComRes, Headline findings—attitudes to sexual health, October 2012
527 Department of Health, Cardiovascular Disease Outcomes Strategy: Improving outcomes for people with or at risk of cardiovascular disease, March 2013
Ev w180  Health Committee: Evidence

Gavin Terry, Policy Manager, Diabetes UK
Dr David Edwards, General Practitioner, Chipping Norton, Oxfordshire; President, British Society for Sexual Medicine
Bharat Patel, Chair, National Pharmacy Association
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9 May 2013

Written evidence from Action on Hearing Loss (LTC 83)

ABOUT US

Action on Hearing Loss is the new name for RNID. We’re the charity working for a world where hearing loss doesn’t limit or label people, where tinnitus is silenced—and where people value and look after their hearing.

Our response focuses on key issues that relate to people with hearing loss. Throughout this response we use the term “people with hearing loss” to refer to people with all levels of hearing loss and tinnitus, including people who are profoundly deaf. We are happy for the details of this response to be made public.

INTRODUCTION

Action on Hearing Loss welcomes the opportunity to provide written evidence on the management of long-term conditions within the NHS and social care system. Hearing loss is a long term condition affecting over 10 million people in the UK—one in six of the population.528 Our recently released evidence-based report Joining up529 showed how large cost savings and improvements to quality of life could be achieved from better provision of health and social care services to people who have hearing loss and also have other long-term conditions.

SUMMARY

— Long-term conditions are not experienced in isolation. 71% of people over 70 years have hearing loss, many of whom are likely to have one or more other long-term conditions. There are also additional associations between some conditions—for example there is strong evidence of a link between hearing loss and dementia.
— Proper diagnosis and management of hearing loss can ensure proper communication with health professionals, access to services and information, and reduce the risk and improve the management of other long-term conditions.
— Health professionals providing care should enquire about whether the person has a hearing loss and refer them on. Hearing checks should be carried out in a range of settings and a hearing screening campaign should be introduced, to ensure people get help for their hearing loss.
— Health and social care services, health promotion campaigns and information should be provided in ways that are accessible to people with hearing loss. Staff should be trained, and communication support and assistive technologies should be provided.
— Better diagnostic tools, specialist services and guidance should be developed to support people with hearing loss who also have other long term conditions.
— Resources should be allocated in a cost effective way. For example, the lack of resource allocated to hearing loss within the National Dementia Strategy for England should be reviewed.
— Such changes could lead to greatly improved management of long-term conditions and large cost savings, by improving communication, lowering the rate of hospital admissions and the need for specialist care, and delaying entry into residential care.

HEARING LOSS AND OTHER LONG-TERM CONDITIONS IN AN AGEING POPULATION

1. Because of the high prevalence of many long term conditions in older people, the numbers of people being affected are increasing, and long term conditions are often not experienced in isolation. For example, one in 14 people aged 65 and over has some form of dementia,530 and at least one in eight has diabetes.531

2. Hearing loss is even more widespread; it affects 10 million people of all ages in the UK—one in six of the population. As our society ages this number is set to grow and by 2031 there will be more than 14.5 million people with hearing loss in the UK.532 Hearing loss has significant personal and social costs and leads to high

528 Action on Hearing Loss, Hearing Matters 2011
529 Action on Hearing Loss, Joining up: Why people with hearing loss or deafness would benefit from an integrated response to long-term conditions 2013, www.actiononhearingloss.org.uk/joiningup
532 Action on Hearing Loss, Hearing Matters 2011
levels of social isolation and consequent mental ill health, and it can increase the risk and impact of other long-term conditions such as dementia. In turn, effective diagnosis and management of hearing loss can minimise these impacts on peoples’ lives.

3. Age-related damage is the single biggest cause of hearing loss, which means that older people are very likely to experience hearing loss. Hearing loss is experienced by almost three quarters (71%) of all people over 70 years, most of whom will benefit from hearing aids and support, allowing them to communicate well and avoid social isolation, and a large number of whom will have one or more other long term conditions. Hearing loss can have particularly significant impacts on the management of other long-term conditions:

1. Unmet communication needs, arising from unmanaged hearing loss, pose a challenge to provision of care and hence the wider management of other long term conditions.
2. People with hearing loss experience greater difficulties in accessing health and social care services and public health information, and receive a lower standard of health service across the board.
3. Unmanaged hearing loss can bring about challenges in terms of the management of particular conditions such as diabetes, where patients can play a large role in self-managing their condition, so effective communication with health professionals is essential.
4. Particular psychological and behavioural challenges can result where people have unmanaged hearing loss alongside other conditions that can cause additional communication difficulties such as stroke, dementia, sight loss or Parkinson’s.

4. It is essential that the high and increasing prevalence of hearing loss and its co-occurrence with other long-term conditions are taken into account as they have implications for the diagnosis, progression and management of people with all long term conditions.

5. Despite the high prevalence of hearing loss and its significant impacts on individuals, especially where they have one or more other long-term conditions, many people who have hearing loss do not seek help. An estimated four million people have unaddressed hearing loss. It takes 10 years on average for people with hearing loss to seek help, and even when they do, 45% of GPs fail to refer them on. It is therefore vital that hearing loss is diagnosed and managed earlier and more effectively, and that services are improved for people with hearing loss and other long-term conditions.

IMPROVING THE MANAGEMENT OF MULTIPLE CONDITIONS

6. Given the high prevalence of many long-term conditions in older groups, we would expect many of these conditions to occur alongside each other. There is also evidence of stronger associations between some of the conditions.

7. In particular, there is now evidence that hearing loss is linked to a decline in cognitive function and dementia. People with mild hearing loss have nearly twice the chance of going on to develop dementia as people with normal hearing, and the risk increases to threefold for those with moderate and fivefold for those with severe hearing loss. Evidence suggests that social connectedness reduces the risk of developing dementia, so it may be the social isolation resulting from unaddressed hearing loss that increases the risk of dementia.

8. Services must become better at treating hearing loss and dementia when they are experienced together. Not only is hearing loss often undiagnosed, but hearing loss may be misdiagnosed as dementia or make the symptoms of dementia appear worse, or dementia may be underdiagnosed because of hearing loss or deafness. Where both conditions are present, their diagnosis, impact and management can be complicated. For example, where unaddressed hearing loss causes communication problems in people with dementia, this
can lead to behavioural and psychological problems which could have been avoided by better diagnosis and management. Both hearing loss and dementia need to be addressed early and when they are diagnosed and treated they should take into account each other’s challenges. For example, one study found that only 5% of care home residents, many of whom had dementia, were able to complete a full audiometric assessment. Specialist diagnostic tools as well as improved management (such as through well-maintained hearing aids and support) are needed.

9. Cardiovascular disease, diabetes and hypertension are all correlated, and there is some evidence that there may be a link between these conditions and hearing loss. This may be due to a lack of access to prevention services and public health information among people with hearing loss and deaf people, suggesting that these services and information should take account of hearing loss and be made more accessible.

10. Where other conditions such as stroke, Parkinson’s and sight loss themselves affect communication, they can compound communication issues in people who also have hearing loss or who are deaf, requiring very specialised diagnostic tools and management. Sudden hearing loss can increase the risk of stroke, and stroke itself can cause hearing impairment, meaning these two conditions are likely to occur together. There is also evidence of correlation between diabetes and hearing loss, and particular implications for the management of diabetes, as patients with diabetes can play a large role in self-managing their condition, so effective communication with health professionals is essential. Given the high levels of co-occurrence, it is crucial that services for cardiovascular disease, stroke, Parkinson’s, sight loss and diabetes take account of hearing loss.

**Designing Integrated Services for People with Long-Term Conditions**

11. Despite the evidence that people often experience long-term conditions together, they are often addressed separately. Government plans have emphasised better management of services for people with long-term conditions, but they have tended to treat long-term conditions in isolation. For example, the National Dementia Strategy for England does not acknowledge the need to manage hearing loss in people with dementia. The planning of services, diagnosis and management for each long-term condition needs to take the others into account.

546 http://www.alz.co.uk/info/diagnosis
547 Burkhalter C L et al., “Examining the effectiveness of traditional audiological assessments for nursing home residents with dementia-related behaviors” *Journal of American Academic Audiology* 2009, 20(9): 529–38
548 Action on Hearing Loss, *Joining up* 2013
553 Action on Hearing Loss, *Joining up* 2013
556 Kulmala J et al., “Poor vision accompanied with other sensory impairments as a predictor of falls in older women” *Age and Ageing* 2009, 38(2): 162–7
559 Atkinson J et al., “When sign language breaks down: Deaf people’s access to language therapy in the UK” *Deaf Worlds* 2002, 18: 9–21
561 Lee H, “‘Sudden deafness related to posterior circulation infarction in the territory of the nonanterior inferior cerebellar artery: frequency, origin, and vascular topographical pattern’” *European Neurology* 2008, 59(6): 302–6
564 Action on Hearing Loss, *Joining up* 2013
565 Action on Hearing Loss, *Joining up* 2013
12. In the case of hearing loss, relatively low cost interventions such as hearing aids can improve communication, quality of life and social relationships.\textsuperscript{572} Hearing aids allow individuals to communicate better with health professionals and ensure that other long-term conditions can be managed effectively. Hearing aids may also particularly help people at risk of or who have dementia, as they may improve cognitive function\textsuperscript{573,574} or slow down the deterioration in cognitive function.\textsuperscript{575}

13. There are a number of steps that are not currently being taken that can allow for the effective management of other long-term conditions among people with hearing loss, improve quality of life, and save money.\textsuperscript{576}

13.1 GPs and all health professionals should be aware of the high prevalence of hearing loss and links between hearing loss and other long-term conditions. They should enquire about whether the person has a hearing loss, cross-refer and cooperate with other professionals.

13.2 Opportunistic and targeted hearing checks should be integrated into other services and settings, such as in pharmacies, care homes, consultations for other conditions, and alongside other health checks at GPs. An adult hearing screening programme for 65 year olds would ensure people manage their hearing loss when they are most able to adapt.

13.3 All health and care providers should ensure that staff are trained in deaf awareness and communication tactics, that proper processes are in place for booking communication support, that assistive technologies are used and that services are accessible to people with hearing loss and deafness.\textsuperscript{577}

13.4 Information, guidance and health promotion campaigns around other long-term conditions should be provided for people with hearing loss and deaf people who use British Sign Language (BSL) in a format that they can access.

13.5. Develop better diagnostic tools, specialist services and guidance to support people with hearing loss who also have other long term conditions, and make sure these are used. For example, audiological assessments for people with dementia have been developed which simplify instructions,\textsuperscript{578} and some audiology departments have adapted their testing procedures so that they meet the needs of people with dementia.

13.6 Ensure that resources are allocated in a cost effective way by properly managing hearing loss in people with other long term conditions. For example, the lack of resource allocated to hearing loss within the National Dementia Strategy for England should be reviewed.

14. These changes could enable significant cost savings—if they resulted in increased awareness, earlier diagnosis, more effective diagnosis, more integrated and personalised care, and better access to services, this could lead to greatly improved management of long-term conditions, lowering the rate of hospital admissions and the need for specialist care, and delaying entry into residential care.\textsuperscript{579}

15. People with dementia and unmanaged hearing loss are at a high risk of requiring a high cost intervention at an early stage. Cost savings could therefore be made through better management of hearing loss, providing services that are accessible to people with hearing loss or deafness, and ensuring that the diagnosis and management of dementia takes a person’s hearing loss into account. Our \textit{Joining Up}\textsuperscript{580} report estimates that ensuing reductions in the need for residential care would save at least £28 million per year in England. Further savings would be made through reducing hospital admissions and the need for specialist care, avoiding delayed or incorrect diagnoses and more effective management and re-ablement.\textsuperscript{581}

16. These cost savings could also be replicated across services managing other long-term conditions, such as diabetes, sight loss and cardiovascular disease.

\textit{9 May 2013}

\textsuperscript{572} Appollonio I. et al., “Effects of Sensory Aids on the Quality of Life and Mortality of Elderly People: A Multivariate Analysis” \textit{Age and Ageing} 1996, 25(2): 89–96


\textsuperscript{574} Mulrow C D et al., “Quality-of-Life Changes and Hearing Impairment” \textit{Annals of Internal Medicine} 1990, 113(3): 188–194

\textsuperscript{575} Allen N H et al., “The effects of improving hearing in dementia” \textit{Age Ageing} 2003, 32(2):189–93

\textsuperscript{576} Action on Hearing Loss, \textit{Joining up} 2013

\textsuperscript{577} Action on Hearing Loss, \textit{Access all Areas? 2013}

\textsuperscript{578} Lemke U, “Hearing impairment in dementia—how to reconcile two intertwined challenges in diagnostic screening” \textit{Audiology Research} 2011 1(1): 58–60

\textsuperscript{579} Action on Hearing Loss, \textit{Joining up} 2013

\textsuperscript{580} Action on Hearing Loss, \textit{Joining up} 2013

\textsuperscript{581} Action on Hearing Loss, \textit{Joining up} 2013
Written evidence from the British Society for Allergy & Clinical Immunology (LTC 85)

We have only recently become aware of this call for evidence. Obesity is an increasing epidemic and is a major issue for respiratory conditions, both in terms of making it difficult for people with respiratory conditions to move about (due to the increased work of breathing and their lack of respiratory reserve, and also through the specific conditions of obesity hypoventilation and obstructive sleep apnoea, both of which lead to hypoxia, hypercarbia (excess CO2), pulmonary hypertension and eventually to right heart failure.

In addition, obesity is an issue in relation to difficult asthma. Beyond the general call for strategies to reduce obesity at the community level, we need better recognition of the role of obesity in making asthma difficult to control—steroids are not the answer in these patients, many of whom have asthma, and are breathless but not due to airways inflammation. Pre-constriction of their airways plays a large part in rendering them wheezy, and they are at high risk of steroid complications if this is not recognised and they are treated (by guidelines) like asthmatics with normal BMI. Education of primary care teams is important, but most of these patients do require specialist support from expert teams (and many secondary care respiratory physicians and A&E doctors are not fully aware of the issues either).

Asthma is an important chronic condition—much of it is mild and can be managed in the community—this has been a major objective for respiratory physicians and allergists since the late 1980s when the first national guidelines for asthma were produced. A significant minority have more severe disease, which either requires large doses of standard therapy or fails to respond to standard therapy. Many of these end up on medium to long term oral steroid therapy.

Within the hospital sector we continue to see those patients whose asthma is difficult to control, either because it is exceptionally severe or because adherence to therapy is poor. And of course we get to see those who have a diagnosis of asthma but do not actually have asthma or those who have more than just asthma—these make up quite a large proportion of those with “difficult asthma” in fact, and the reason they don’t get better with standard anti-asthma drugs is because they don’t have asthma or at least there is more to their symptomatology than just asthma. Failure to recognise this leads to poor control AND to excessive side-effects from over-reliance on oral steroids to control symptom flares.

Better management of these patients requires recognition of the problem by primary and secondary care physicians, and an acknowledgement that this goes beyond the expertise of most secondary chest physicians (although they do not always realise this). Within the specialist services commissioning framework there are plans for a network of tertiary centres whose primary function is to review these patients, separate the wheat from the chaff and get them into appropriate management pathways. While the allergy community feels the number of centres needed to do this should be larger than the number envisaged in the original proposal from the CRG, we accept the general principle that these patients require multidisciplinary assessment by expert teams and should not be managed in conventional general chest clinics.

Turning to the definition of Chronic Long-Term Conditions, I am not clear whether allergic conditions are regarded as CLTCs for the purposes of this inquiry. The call definition says “those conditions that cannot, at present, be cured, but can be controlled by medication and other therapies. The life of a person with a LTC is forever altered—there is no return to “normal.”

On this basis, most non-acute medical conditions would fall into consideration. Chronic eczema would definitely fit in; chronic asthma has been discussed above; maybe chronic rhinosinusitis and perhaps seasonal allergic rhinitis should be included, as in most cases they cannot be cured, but they can be contained, either by drug therapy or by specific desensitisation.

Food allergy is intermittent in its presentation, but it has a long term impact on patients and their families, adversely affecting their quality of life.

In view of the very short time-line for submitting evidence, I hope these thoughts are useful. I and my colleagues within the British Society for Allergy & Clinical Immunology would be pleased to expand on anything within this letter.

15 May 2013

Written evidence from The Association of British Neurologists (LTC 86)

The Association of British Neurologists and the Royal College of Physicians Joint Clinical Neurosciences Committee, working with the Neurological Alliance has Long Term Neurological Conditions as a high priority given the failure of the DoH to implement the NSF for LTNC and the negative reports last year from the National Audit Office and Public Accounts Committee.

Our concerns remain high given the on-going uncertainty regarding the commissioning of neurological services. We note that the Common’s Select Committee intends to concentrate on Diabetes. The overlap with
neurological conditions such as epilepsy, Parkinson’s disease, multiple sclerosis, traumatic brain and spinal injury, motor neurone disease and migraine is relatively small.

14 May 2013

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**Executive Summary**

- Treatment innovation has transformed HIV into a long term condition.
- The management of HIV requires special consideration due to its infectious nature.
- Ageing in HIV presents significant challenges for the NHS in terms of managing care, complex treatment plans and co-morbidities.
- HIV treatments are cost effective because they significantly reduce the risk of onward transmission and HIV related illnesses. However a major threat to the effectiveness of HIV treatment is non-adherence.
- New treatments may improve adherence which in turn may ensure patients are healthier, require fewer hospital admissions, and reduce the risk of transmission. All of these outcomes improve value for money for the NHS.
- If we do not continue to innovate and invest in HIV, there may be a reversal of the progress we have made so far and an escalation of HIV over time.

**Introduction**

1. Gilead is a leading provider of HIV medicines to NHS patients. We welcome the opportunity to respond to the Health Select Committee’s inquiry into the management of long term conditions. Our response focuses on the effectiveness of service provision and treatment for people with HIV.

2. HIV treatment has advanced dramatically in the decades since the discovery of the virus. Patient prospects have improved considerably and patients can now expect to have a near normal life expectancy. As patients are living longer with HIV their needs are changing. This means the number of patients and overall costs are rising rapidly.

3. Unlike many other long term conditions, HIV is also infectious. To slow the increase in the number of patients and costs, a two-pronged strategy of early diagnosis and access to treatment is required. Late diagnosis, by contrast, is associated with a greater risk of hospitalisation and AIDS-related illness, reduced life expectancy and increased cost to the NHS. It is also associated with increased onward transmission, and continued sexual risk-taking while people are unaware of their HIV-positive status.

4. Gilead recommends the development of a comprehensive strategy for HIV, that will update current NHS practice in line with the treatments and services patients require today. Further innovation will enable patients to better manage their condition, prolong life expectancy and reduce the risk of transmitting the virus to others.

**Ageing and HIV**

5. Since 2000 there has been a three-fold increase in the number of individuals accessing HIV care and a fourfold increase among people over the age of 50.\(^{582}\) This presents significant challenges for the NHS in terms of managing care, complex treatment plans and co-morbidities.

6. Current scientific debate on the impact of HIV related premature ageing suggest that we will see an increasing incidence and prevalence of common age related co-morbidities (such as cardiovascular disease, coronary heart disease, chronic kidney disease and cancers). This will require the need for less toxic HIV treatments with fewer drug-drug interactions.

7. The issue of changing patient needs are particularly relevant given the reality of the ageing HIV patient population in the UK over the next five years. Currently many existing medications for common medical conditions have drug interactions, are contraindicated for certain HIV treatments and/or require enhanced diagnostic monitoring.

8. It is important that we develop new HIV treatments that can be safely used alongside medicines for other common medical conditions to protect patients and reduce the strain on the healthcare system.

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\(^{582}\) HIV in the United Kingdom: 2010 Report, Health Protection Agency, November 2010
Adherence to Treatment

9. HIV treatment is highly cost effective, reducing the risk of onward transmission by 96%583 and HIV related illnesses by 41%. However a major threat to the effectiveness of HIV treatment is non-adherence. Adherence to treatment is very important in helping to ensure a positive outcome for patients.584

10. There are a number of factors that inhibit patient adherence to treatment, among them: impact of side effects, fear of disclosure of their HIV status, substance abuse and difficulty in managing multiple tablets.585

11. Missed doses of treatment have been shown to lead to treatment failure,586 increasing both the rate of progression to AIDS587 and the risk of resistance to treatment.588 Non-adherence has been shown to make patients almost twice as likely to require hospital admission.589 An increase in adherence by just 10% has been shown to reduce the risk of progression to AIDS by 28%.590

12. Given all these factors, supporting full adherence to treatment is a key factor in the long-term affordability of high quality care. New treatments that are easier to manage and have reduced side effects will be important in helping to achieve consistent adherence to maximise virological suppression, improve patients’ quality of life and helping to minimise healthcare resource use.

Conclusion

13. Gilead recommends the development of a comprehensive strategy for HIV, that will update current NHS practice in line with the treatment and services patients require today. The strategy should include the development of appropriate quality measures focused on quality of care and patient experience and choice.

14. In particular, the increasing and ageing population with HIV presents an urgent need for services to be adapted to meet future demand.

15. Patients must continue to have early access to the treatment regimens of their choice and support to remain adherent to treatment plans in order to improve the quality of long-term outcomes, reduce avoidable poor health, minimise the risk of onward transmission and manage costs to the NHS.

13 May 2013

Written evidence from the British Society for Rheumatology (LTC 88)

The British Society for Rheumatology (BSR)591 exists to promote excellence in the treatment of people with arthritis and musculoskeletal conditions and to support those delivering it. As a professional association representing those specialising in rheumatic and musculoskeletal conditions, BSR aims to improve standards of care in rheumatology.

The BSR welcomes the opportunity to contribute to this timely, necessary and important inquiry.

Key Points:

— Rheumatic diseases are a common, yet under-recognised cause of preventable long-term health impacts and disability ages in the UK.

— Early treatment and service coordination across all health and care sectors offers potential to improve patient experience, improve clinical outcomes, and make significant cost savings.

— There are major variations in rheumatology service provision throughout the UK and compared internationally; however we can highlight best practice approaches that are proving successful.


589 Fielden, S.J., et al., Nonadherence increases the risk of hospitalisation among HIV-infected antiretroviral naïve patients started on HAART, 2008


591 BSR website: http://www.rheumatology.org.uk/
THE IMPACT OF RHENUTIC DISEASE

1. Rheumatology is a multidisciplinary branch of medicine that deals with the investigation, diagnosis and management of patients with rheumatic diseases and other musculoskeletal conditions. This incorporates over 200 disorders affecting joints, muscles and soft tissues, including autoimmune disorders and spinal pain. A significant number of rheumatic conditions also affect other organ systems.

2. Rheumatic diseases are often under-prioritised, in part due to low levels of public awareness about what rheumatology is. A recent survey conducted by the American College of Rheumatology indicated that the word “Rheumatology” is for the majority of public participants not known. For others it was commonly associated with foot doctors/podiatry, or viewed solely as an issue relating to old age. In the UK, the low profile of rheumatology is reflected in the fact that it is only mentioned once in the Department of Health's Long Term Conditions Compendium. 592

3. Despite low awareness, musculoskeletal conditions are the the single biggest cause of disability, accounting for 31% of the total UK burden. In contrast to encouraging improvement trends for premature mortality, the UK trend for chronic disability burden is getting worse. In a recent international comparison of disability adjusted life years in developed countries with similar economies, the UK ranks a mere 16 out of 19 for osteoarthritis, and 15 out of 19 for low back pain. 593 Coupled with the known health service challenge of an ageing population, it is therefore vital to reverse the trend of avoidable disability through the quality improvement of rheumatology services.

4. A key issue to address is the collection of data, which has failed to evolve over time to take account of the transformation in rheumatology treatment options. Patients with rheumatic disease used to occupy a great number of hospital beds; however drug therapy now allows the provision to be largely ambulatory. Commissioners therefore have little to inform their service specifications, and there is insufficient public health epidemiology data to inform Joint Strategic Needs Assessments. The fact there are over 200 conditions can further hinder understanding and therefore the BSR has created a simpler domain and pathway approach.

5. Although rheumatology services no longer services are no longer mainly inpatient rehabilitation services involving hospital admission, the potential for Quality, Innovation, Productivity and Prevention (QIPP) savings remain significant, as £680m was spent on drug therapy in England alone in 2012. Savings come from treating people to NICE and national standards and early diagnosis and intervention, and include:
   (a) reduction in the need to use expensive biologics for advancing disease;
   (b) reduced need for joint replacements, as combined cost of hospital and social care for patients with a hip fracture amounts to more than £2.3 billion per year in the UK;
   (c) reduced health and social care costs (including nursing home requirements) for disability caused by high disease activity;
   (d) and reduction in the percentage of all patients (currently a third) unable to work within two years of diagnosis. 594 The Health and Safety Executive estimated in 2011 that over nine million working days are lost each year from work-related musculoskeletal disorders. The estimated cost to the economy of sick leave and work-related disability for people with rheumatoid arthritis is £1.8 billion a year.

6. Below we outline some examples in which rheumatology services have been configured to offer the patient benefits and reduced costs outlined above. However service provision remains varied throughout the UK; the challenge is therefore to enable the delivery of consistently excellent services.

EARLY INTERVENTION AND THE INTEGRATED CARE PATIENT PATHWAY

7. Unlike other services which can be wholly community-based, effective rheumatology services require integrated care along the whole patient pathway, across secondary, community and primary care. This is due to the diagnostic infrastructure required, and the complexity of autoimmune diseases which can affect multiple organ systems. 595

8. Wherever rheumatology services are delivered, there needs to be an extensive diagnostics infrastructure in place incorporating MRI, ultrasound/X-ray and complex blood testing. Unless there is a major investment in community diagnostic centres, this will continue to be provided in acute or community hospital settings. The benefit of having these diagnostic tools in a “one-stop shop” is that the patient avoids the inconvenience of multiple appointments (and associated multiple costs) and the crucial time period from symptom onset to treatment is minimised.

594 NICE guideline for rheumatoid arthritis: http://publications.nice.org.uk/rheumatoid-arthritis-cg79

The Health and Safety Executive estimated in 2011 that over nine million working days are lost each year from work-related musculoskeletal disorders. The estimated cost to the economy of sick leave and work-related disability for people with rheumatoid arthritis is £1.8 billion a year.
9. Early intervention is clinically significant in rheumatology. Up to three months after symptom onset, rheumatic diseases can be treated effectively (to a low level or remission) with relatively inexpensive disease-modifying antirheumatic drugs (DMARDS). A treatment delay of more than three months can result in a more aggressive course to the disease which causes long term damage to joints, and requires expensive biologic treatments.

10. Although the NICE guideline requires that patients are put onto DMARDS within three months of symptom onset, a NAO report in 2009 found that this happens with only 10% of patients. This is in part due to delays in being seen by a rheumatologist and partly due to local differences in the access level to key drugs. The average delay in the UK in GP surgeries is around nine months, by which time joint damage in aggressive disease has already occurred.

11. The same report concluded that only 63% of patients in acute trusts provided annual review for Rheumatoid Arthritis patients to monitor disease progression and emergence of co-morbidities. This indicates that there is some way to go in integrating care for ongoing management of patients with rheumatic disease, as well as initial diagnosis and treatment.

12. The significance of this is shown in a recent National Rheumatoid Arthritis Society (NRAS) recently report that highlights the range and impact of comorbidities associated with rheumatoid arthritis, and demonstrates the extent to which rheumatology services need to be linked to other specialist and community services in a coordinated and holistic manner. Key points from this report include the following:
   (a) Around 80% of rheumatoid arthritis (RA) patients will have one or more co-morbidities.
   (b) The risk of heart attack is doubled for RA patients. The risk of atrial fibrillation is around 40% higher among RA patients than those without RA. The risk of stroke is 30% higher for RA patients.
   (c) Interstitial lung disease associated with RA is a major cause of death amongst RA patients.
   (d) Rates of osteoporosis can be up to twice as high amongst RA patients than the general population.

13. Most financial incentives for good practice in the current system only focus on parts of the pathway—discrete pieces of care as opposed to the whole patient care package. This approach is a key system barrier to the principle of integrated care.

COMMISSIONER SUPPORT, AND BEST PRACTICE EXAMPLES

14. The BSR have joined with Arthritis Care and NRAS to form the Rheumatology Commissioning Support Alliance—a project funded by the Department of Health to support commissioners and develop tools to demonstrate how better services for patients and better value for the NHS can both result from a more service-user-centred approach.

15. The BSR has also recently launched a Commissioning Toolkit for Providers. This package aims to help rheumatology professionals develop their knowledge and skills to design effective services and make the most of commissioning opportunities.

16. In addition to the initiatives above, the BSR is proactively developing a hub of good practice service models. We intend to publish case studies in the autumn, however in advance of this we outline two models below that give a flavour of current initiatives being delivered in the UK.

17. Site A example:
   (a) Standardised whole patient pathway that meets all NICE and European standards.
   (b) Single set of patient records between doctors and the multi-disciplinary team (MDT).
   (c) Hand-held patient records for decision making
   (d) Early cognitive behavioural therapy regarding first-stage disease perception.
   (e) The first eight weeks of drug therapy are prescribed by GPs after diagnosis—primary care is the first part of the pathway with an agreed protocol.
   (f) The patient is a partner in treatment and goes to all meetings including research.
   (g) There is a specialist nurse care co-ordinator across acute, community and primary care. This includes a hot line and direct access for GPs and patients, enabling self-care, helping people stay in the community and enabling rapid response to disease flares.

18. Site A outcome: reduced work loss due to depression and anxiety, and 40% reduction in the need to use expensive biologic drugs.

19. Site B example:
   (a) Working with community pharmacy to reduce medicine costs incurred through wastage and expiry.
   (b) A “treat to target “ biologics approach (personalised prescribing based on individual patient data as opposed to standard drug and dosage regimes).

(c) Patient partner training for over 2000 GPs to enable better referral.

(d) There is a specialist nurse care co-ordinator across acute, community and primary care. This includes a hot line and direct access for GPs and patients, enabling self-care, helping people stay in the community and enabling rapid response to disease flares.

20. Site B outcome: Savings of over a quarter of a million pounds per year over the last three years. These are shared between the commissioner and provider.

21. The BSR is happy to expand further on any of the points raised in this submission.

13 May 2013

Written evidence from the British Association of Dermatologists (LTC 89)

The British Association of Dermatologists is a charity whose objects are the practice, teaching, training and research of Dermatology. It is funded by the activities of its Members. “Healthy Skin for All” is its motto.

1. DERMATOLOGY—LONG TERM CONDITIONS (LTCs)

Many skin diseases themselves represent LTCs.

People with LTCs in other organs or systems commonly get skin disease.

Some skin LTCs are associated with increased physical and psychological disease.

The available dermatological resource is already seriously overstretched.

— Many skin diseases themselves are LTCs. Examples include psoriasis, eczema, acne, vitiligo, leg ulcers and chronic sun damage resulting in multiple skin cancers.

— Chronic skin conditions affect both the young and old and may persist over the course of a lifetime.

— The burden of chronic skin diseases such as leg ulcers and repeated episodes of skin cancer is increasing as the population ages.

— Skin disorders are amongst the most common long-term conditions in the UK: there are more than 2,000 different diseases.

— There is a large number of genetic skin diseases; each one may only affect a small number of people, but taken together they form part of the long term skin disease burden in the UK.598 For sufferers they are a life sentence of misery, physical and cosmetic disability and psychological challenges.

— Skin diseases represent 34% of disease in children.599 20% of children in the UK have eczema,600 children with serious skin conditions have their quality of life impaired to the same extent as those with chronic illnesses such as epilepsy, renal disease and diabetes.601

— Acne is an extremely common skin disease—often trivialised as a “passing phase” of adolescence—yet it commonly persists into the 20s and even 30s and 40s in many people (up to 5% of all women). Acne scarring is permanent. Acne results in long term disabilities including difficulties in relationships and employment prospects.

— Hand eczema is one of the most common reasons for disablement benefit in the UK.602

— 3% of the population has psoriasis (with a third suffering since childhood). 30% of psoriasis patients needing systemic treatments have been attending Dermatology clinics for over 10 years.

— Some lifelong diseases such as vitiligo, which results in the loss of normal skin colour, can have a devastating effect on self-esteem for people from black and ethnic minorities.

— It is estimated that several million people in the UK have significant chronic sun damage resulting in ~13,000 melanomas and ~800,000 basal cell and squamous cell skin cancers a year.

— People with chronic sun damage suffer increasing numbers of skin cancers as they age—the ageing population will have a bigger incidence of this disease.603

599 _Consultant physicians working with patients, Royal College of Physicians 2011: http://www.rcplondon.ac.uk/sites/default/files/dermatology_1.pdf
— Chronic skin disease can influence “major life changing decisions”, which then impact on the rest of a person’s life.\textsuperscript{604}

— In the UK, data from the WHO Global Burden of Diseases study shows that DALYs (Disability Life-Adjusted Years) for skin conditions are as high as those for diabetes, chronic renal disease, gastrointestinal disorders or neonatal abnormalities. The reason is largely because skin disease is so common.\textsuperscript{605}

— People with LTCs in other organs or systems (eg diabetes, HIV, transplants, cancer) commonly get skin disease:

— Patients with chronic disease can be affected by skin disease directly due to the effects of those diseases (eg diabetes and HIV).

— People with other LTCs also get skin problems due to their treatments. This is especially common when treatment includes drugs such as anti-epileptics, cancer therapies and radiotherapy, or transplants—due to the drugs given to prevent transplant rejection.

— Increasingly in an ageing population people are on multiple medications; dermatological side-effects are extremely common, ranging from chronic itching and rashes, to life threatening conditions warranting hospitalisation.

— People with LTCs in other organs or systems (eg diabetes, HIV, transplants, cancer) commonly get skin disease;

— Some skin LTCs (eg psoriasis) are associated with increased physical and psychological disease.

— Patients with chronic psoriasis have increased obesity, hypertension, hypercholestaemia, diabetes, heart disease (the metabolic syndrome) and mortality. 20% of patients with psoriasis develop chronic arthritis.

— In the United Kingdom, in excess of 10,400 diagnoses of depression, 7,100 diagnoses of anxiety, and 350 diagnoses of suicidality are attributable to psoriasis annually.\textsuperscript{606}

— The available dermatological resource is already seriously overstretched;

— 24% of the population consults a GP each year because of a skin complaint. Skin disease is one of the most common reasons for a new consultation with GPs.

— GPs refer approximately 6.1% of these cases to secondary care and in 2010/11 873,000 such referrals were made in England with 2.9 million total outpatient appointments for skin diseases.

— There is a 20% under-provision of Dermatology services in the UK: with only 650 Consultants in the country.

— Despite the above statistics, GPs receive on average no more than six days training in Dermatology during the whole of their time as undergraduate and post-graduate medical students, and only around one in five GP training schemes offer a Dermatology element.\textsuperscript{607} It is therefore inevitable that many doctors will enter General Practice with limited knowledge and understanding of common skin diseases that can often present significant clinical diagnostic and management problems.

— Referrals to Dermatology services have risen as a consequence of increasing population numbers, frequency of skin diseases, improved treatments and changing attitudes to skin conditions. This is despite the increased number of community based services following the recommendations of the White Paper “Our health, our care, our say: a new direction for community services” (2006).

2. VARYING THE CURRENT MIX OF SERVICE

2.1 In the BAD’s document “Guidance for Commissioning Dermatology Services” we set out the range and scope of services which would best serve Dermatology patients at different levels, including Community Pharmacists and Specialist Nurse-led clinics supporting patients with self-management, and covering primary and intermediate care to secondary and tertiary services. The BAD supports the provision of a comprehensive mix of services but not the promotion of one type of service over another—there will always be a need for centralised hospital-based services. These continue to be the most cost-effective and safe means of providing direct access to care for patients who are acutely unwell and have complex care needs. Increased Consultant-led community services and education of primary care doctors and nurses will all help to improve integrated care of patients through a pyramid of appropriate expertise, so that patients see the right person at the right time.


\textsuperscript{605} United Kingdom Performance on Health: Implications from the Global Burden of Disease Study 2010 The Lancet, Volume 381, Issue 9871, Pages 997—1020, 23 March 2013 doi:10.1016/S0140-6736(13)60355-4

\textsuperscript{606} The Risk of Depression, Anxiety, and Suicidality in Patients With Psoriasis A Population-Based Cohort Study CHOSIDOW OLIVIER, MD, PhD; P. DELLA VALLE ROBERT, MD, PhD; DO DAIHUNG, MD; GONZÁLEZ URBÁ, MD, PhD; M. POPESCU CATALIN, MD, PhD; WILLIAMS HYWEL, MSc, PhD, FRCP; Shanu Kohli Kurd, MD, MSCE; MHS, Andrea B. Troxel, ScD; Paul Crits-Christoph, PhD; Joel M. Gelfand, MD, MSCE Arch Dermatol. 2010;146(8):891–895. doi:10.1001/archdermatol.2010.186.

\textsuperscript{607} Chiang Y et al Burge SM 2008 BJD 159 Suppl 1p 1.
3. The Readiness of Local NHS Services to Treat Patients with LTCS (including Multiple Conditions) within the Community

3.1 The lack of dermatological training at undergraduate and postgraduate level for GPs has the knock-on effect that provision in primary care is limited. Although a number of intermediate services have been set up in the community and are staffed by a range of healthcare professionals such as GPwSIs, these should be developed in partnership with secondary care. The location, service model and range of facilities dependant on local needs should be assessed prior to implementing service redesign. The cost effectiveness and quality outcomes of such services should also be evaluated. For example, clinics provided by GPwSIs can be more expensive than secondary care services.

3.2 Clinical Assessment and Treatment Centres are also used in some areas to triage and/or review GP referrals to reduce the number of patients referred to secondary care. The BAD recommends that GP referrals are always triaged by a Consultant Dermatologist with GPwSI and Dermatology nurse support, and that referral management services should only be set up after consultation with all stakeholders, including the public and those in secondary care. Without engagement at all levels, referral management services may introduce an additional tier to accessing care, reduce patient choice and quality of care, and worse still, destabilise local NHS hospital services.

3.3 Providing Care Closer to Home often involves decommissioning parts of Dermatology Outpatients services in order to provide intermediate levels of care in the community. However, the objective of such decommissioning—to bring about improvements in service provision—has not been realised. Instead, there are increased referrals to both community and hospital services, rather than reduced referrals to the hospital setting. Under the existing Any Qualified Provider model, and with the use of private providers, recognised care pathways across different levels of care can become fragmented. This happens even when these services are provided by local clinicians under a Limited Liability Partnership. In the majority of cases where this has happened the cost of care remains the same per head of patients as the hospital service. This cost does not, though, factor in the additional costs for patient care for those “lost” on the referral pathway between their GP and the community, before getting to secondary care.

3.4 Although moving care closer to home has been a policy ambition for some time, referral rates to both community and secondary care services have continued to rise since its inception, and there are worrying signs that primary care is buckling under the current pressures of demand.

4. Practical Assistance Offered to Commissioners

4.1 The BAD has produced the document “Guidance for Commissioning Dermatology Services” (2012) which can be downloaded from the BAD website (www.bad.org.uk), and the Clinical Services Unit provides individual support to Commissioners, stakeholders and Dermatology Departments on commissioning issues. From this service and the case studies received, the unit has now produced a document called “Commissioning a Dermatology Service: Lessons for the NHS” which draws together learning from case studies, and provides reflections and recommendations that will be of practical use to Commissioners.

4.2 Quality Standards for Dermatology; providing the right care for people with skin conditions is a multi-stakeholder (including the BAD) publication and is available on the PCC website and has implications for commissioning.

5. The Ability of NHS to Treat Multi-Morbidities and the Patient as a Person

5.1 Patients with skin disease often require treatment for existing co-morbidities (for example psoriasis and the metabolic syndrome) by their GP and Dermatology and other specialists; these patients need to be identified because they impact on services across the levels of care and across specialties. A Needs Assessment is therefore a crucial step in drawing up service specifications.

5.2 Dermatologists are frequently required to review patients under other specialist departments where treatments, both pharmacological and otherwise, can cause side-effects presenting as skin problems—often causing extra distress, physical morbidity and risk to an already sick individual. Drug reactions in skin are a common reason for admission to hospital and sometimes can be life-threatening. Immunosuppression (for example in HIV, AIDS or following organ transplants) as well as treatments for other cancers and diseases have all led to an increase in the number of people developing skin complications, including secondary skin cancers.

5.3 Identifying these dermatological co-morbidities (and their treatment) from coded information is particularly problematic as the patient under care will be logged under another specialty or consultant. The majority of Trusts have divisional budgets, (entitled, for example, General Medicine, Medical Specialties, or hosted by another specialist department eg Plastic Surgery), this fails to recognise the work of the Dermatology Department because it does not allow a) the identification of multidisciplinary care pathways or b) accurate planning of services by the Trust and Commissioners.

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609 Kings Fund “Shifting care closer to home: slogan or solution?”
5.4 Recognition of multi-disciplinary care pathways should be highlighted to Commissioners considering services with a high level of multiple morbidities in certain patient groups. Within the NHS flexibility and integration have evolved around on-call services and in-patient consultations—if these services are contracted to private providers then the additional costs associated with these ad-hoc consultations would need to be factored in.

6. THE IMPLICATIONS OF AN AGING POPULATION

6.1 Growth of the ageing population will increase the prevalence of skin LTCs. This is highlighted by the DALY statistic—although this captures disability over the entire population, ie young and old, and over time, one of the reasons why diabetes is less disabling is that it has higher mortality, whilst those with skin conditions continue to live with them into old age, increasing the DALY numbers.

6.2 The skin cancer epidemic gathers pace. The vast majority of skin cancer is due to chronic photo-damage as a result of increased recreational exposure and this shows no signs of diminishing. Many patients will have several episodes of skin cancer and pre-cancer as they get older. There are about ~13,000 melanomas and ~800,000 other skin cancers a year in the UK.

6.3 With increasing population growth and increasing longevity it is important to invest in Dermatology services, and training in Dermatology, so that the burden of chronic skin disease can be better managed with better outcomes for all patients. This includes the elderly and those whose skin disease is due to an associated LTC and/or its treatment.

7. THE INTERACTION BETWEEN MENTAL HEALTH CONDITIONS AND LTCs

7.1 The BAD recognises the strong inter-relationship of mental health conditions with long-term physical health conditions, and particularly with skin conditions that are often both disabling and disfiguring. It is also important to acknowledge that patients may present with a skin condition which masks an underlying, untreated mental health problem. The recent BAD document “Working Party Report on Minimum Standards for Psycho-Dermatology Services 2012” outlines key information on psychosocial support service delivery requirements. The report delineates minimum service standards for psychosocial support.

7.2 The BAD has also recently been awarded, a Department of Health Innovation, Excellence & Strategic Development Fund grant to create a web-hub to provide psychological support to those suffering with skin conditions.

7.3 It should be highlighted that both these pieces of work have been driven by the under-provision of dermatology psychological services. A recent study showed that 17% of patients needed psychological support to help them cope with psychological conditions secondary to their skin condition, 14% of patients had psychological conditions exacerbating their skin condition, 3% of patients presented with primary psychiatric disorders, and 8% had worsening psychiatric problems due to concomitant skin disorders.

8. CONCLUSIONS

Skin disease contributes hugely to LTCs in the UK; millions of people have dermatological LTCs such as eczema, psoriasis, acne, vitiligo and occupational skin disease. Additionally, there is a growing sector of the ageing population with chronic sun-damage and the serial skin cancers that ensue. Many other primarily non-dermatological LTCs create significant dermatological needs, due to the disease itself or to its treatment with drugs and their consequences and side effects. Some dermatological LTCs, especially psoriasis, are associated with significant co-morbidity—the metabolic syndrome and arthritis.

Provision of the type of care affected people need is under-resourced, fragmented and of variable quality, in terms of manpower and facilities. This is exacerbated by poor teaching and training of Dermatology in Medical Schools and General Practice, and under-funding of relevant research.

Addressing these issues of resource, training and research should lead to greatly improved care for people with LTCs delivered by Consultant-led, vertically integrated services.


611 (Study details: "Psychocutaneous medicine and its provision in the UK"; A P Bewley, C Fleming and R Taylor; Barts and the London Trust, London, UK)
Health Committee: Evidence  Ev w193

NOTES
The BAD documents referred to above can be found at: www.bad.org.uk under the Clinical Services menu.

Quality Standards for Dermatology; providing the right care for people with skin conditions can be found on the PCC website http://www.pcc-cic.org.uk/article/quality-standards-dermatology
13 May 2013

Written evidence from Accenture (LTC 90)
Accenture welcomes the opportunity to respond to the Health Committee’s call for written evidence. With a global Health practice comprising over 15,000 professionals, we work with 35 Trusts in England, 23 of the 25 Health companies in the Fortune Global 500, and public, private and community health providers in in Brazil, Finland, France, Germany, Italy, Norway, Spain, The Netherlands, US, Canada, Australia and Singapore.

SUMMARY
— The NHS is under pressure to deliver high quality care and significant savings, whilst at the same time dealing with increasing populations of patients with long-term conditions.
— To address this, a transformation is needed in the way health and care services deal with chronically ill patients.
— We believe that this requires a comprehensive response that combines integration of services across the health sector with proven, patient-centric health management interventions.
— There are strong examples of the impact such an approach can have on improving patient outcomes and significantly reducing costs, and we have detailed a number of national and international examples below.
— To enable the implementation of this model quickly and at scale, integration and health management needs to be prioritised by commissioners, collaboration is needed across health and social care, and technology needs to be harnessed to enable effective integration.

The scope for varying the current mix of service responsibilities so that more people are treated outside hospital and the consequences of such service re-design for costs and effectiveness

The imperative for service transformation is clear

1. The NHS is experiencing increasing pressure on resources. Trusts are serving a growing population of patients with complex and long-term conditions, a group who are already costing the NHS in excess of £70bn every year, 70% of the total health and care budget.612

2. In addition, the recent Francis Report led to increased scrutiny of the quality of care received, rightly leading to a renewed focus on patient outcomes, and this is happening at the same time that Trusts are seeking substantial savings. We concur with the general consensus that in order to address these competing challenges, service transformation is needed, principally through vastly improved integration of health and care services.

3. Yet despite this consensus, the urgency for change, and a growing evidence base for the impact integrated care and health management can have,613 the delivery of this model of care in the NHS has not happened at scale.

4. We believe, based on our experience both in the NHS and globally, that there is scope to vary the current mix of services. We believe that integrated health and care services can become the standard in the NHS, but several issues restricting implementation need to be addressed in order to achieve this.

Recommendations for enabling at scale delivery of integrated care

5. There are a number of financial, structural and design challenges that are currently making implementation difficult. Addressing these would enable the delivery of integrated care at significantly greater scale and pace.

5.1 Putting integration and health management at the top of the investment agenda
— Removing disincentives to investment: the tariff structure for the acute sector disincentivises investment in preventative activity. Income is generated from the treatments delivered within an acute setting, but consideration should be given to how hospitals can be rewarded for preventing those admissions.

612 Jeremy Hunt, Secretary of State for Health, Will we rise to the challenge of an ageing society?, 25th April 2013
613 3 million lives; Whole system demonstrator; Torbay (Kings Fund)
Ev w194  Health Committee: Evidence

— Incentivising cross-agency collaboration: the benefits of integration and health management accrue across health and care organisations, but to release these benefits investment in services and infrastructure is needed. Our experience to date shows that whilst there is agreement amongst health organisations on the value of integrating services, organisations are unclear who should be taking ownership of delivering it. However, with the establishment of Clinical Commissioning Groups (CCGs) and Health and Wellbeing Boards (H&WBs), and with integration a key priority for NHS England, this presents an opportunity to drive the agenda forward. Commissioners need to work together to invest in integrated care as a priority, with CCGs recognising that commissioning community health management solutions will significantly increase patient outcomes and relieve pressure on the acute sector.

5.2 Identifying excellence in integrated care and enabling delivery at scale

— Identifying an evidence-based pathway for integrated care: there are currently multiple, small-scale projects piloting different models of integrated care. Whilst there is clear value in testing different approaches and any model must take into account local needs, in order to achieve a significant increase in the scale and pace of implementation commissioners need a shared vision of what excellence in integrated care looks like. The development of a clear, evidence-based pathway for non-acute treatment of patients with long-term conditions would provide the confidence for commissioners to press ahead with procuring services.

— Enabling scale and value for money: identifying excellence in integrated care pathways would also enable commissioners to join together to co-commission the necessary infrastructure, thereby harnessing the benefits of scale: cost reduction and a larger population to measure outcomes.

5.3 Enabling integration through technology:

— Delivering on one patient one record: a key challenge for professionals working across the health and care sector is access to patient information. This is particularly important for vulnerable patients with multiple chronic conditions. Electronic Medical Record systems should be compatible across health providers, from acute to community, in order to ensure patients receive the right treatment at the right time—avoiding unnecessary hospital admissions and lengthy stays resulting from a lack of awareness of a patient’s medical history.

6. Health providers around the world are facing the challenge of increasing populations with long-term health conditions and are therefore examining new solutions to re-design services in a patient-centric and cost-effective manner. We believe that international examples can usefully inform the delivery of services in England, and that these models could readily be replicated by the NHS. To illustrate this, we have provided a case study of our work in Valencia.

VALENCIA, SPAIN: ADAPTING EXISTING CARE MODELS TO BETTER MANAGE CHRONIC CONDITIONS AND THEIR IMPACT ON PUBLIC HEALTH

7. Accenture has been working in partnership with La Fe University Hospital to implement an 18 month clinical trial to redesign the care of patients with multiple, complex chronic diseases. 60% of spending goes to only 4.5% of patients and the vast majority is spent on acute treatment. La Fe’s aim is to assess how health services can be redesigned in a safe and cost-effective manner to (i) avoid patients entering the acute setting in the first place, and (ii) reducing length of stay in the acute setting by proactively supporting their treatment via non-clinical measures.

8. To reduce unnecessary hospital visits, we implemented a case management function to remind patients of appointments and support them in following their treatment plans, and established a helpline for patients to contact us by phone to discuss questions or concerns.

9. To further drive down admissions, we are working with the hospital, using advanced Analytics, to predict which patients are most likely to have acute episodes. These patients are then targeted for enrolment in the case management programme and receive continuous support and proactive management of their symptoms in the community. This significantly reduces the chance of an exacerbation of chronic disease symptoms leading to costly acute episodes.

10. Preliminary results in Valencia are promising showing a reduction in A&E visits from 5 to 0.9 and preventable inpatient days by 70–80%. These care improvements for chronic patients also contribute to significant cost savings of around €18,000 to €5,000 (per patient pa). The figures are indicative and preliminary at this point and we will provide the figures to the Committee when they become available.

11. This model could easily be replicated in England. Case management already exists in community healthcare, administered by district nurses working with a case management model. Cambridge University Hospital (CUH) so far is the only acute hospital to have implemented it with strong results (see below).

615 Department of Health, Integrated Care Pilots, 12 March 2012
616 Reduction in unplanned, predictable visits due to exacerbation of chronic disease symptoms
12. Technology and health analytics (already used across the UK public sector) would further “future-proof” the system by identifying patients at high risk of future acute episodes, reducing hospital admissions and delivering better patient outcomes at considerably less cost.

Current examples of effective integration of services across health, social care and other services which treat and manage long-term conditions

13. There are a number of examples of effective integration to treat long-term conditions, however the approach has been fragmented, with different areas implementing different elements.

14. We believe that to have the biggest impact the approach should be two-fold:
   — Comprehensive integration and coordination of activities between health and care providers in the primary, acute, community and social care setting.
   — End-to-end health management that treats the patient not the condition.

15. The diagram below demonstrates the different actors and interventions needed to deliver truly effective integrated care:

Illustrating the Model: Treating Diabetes through Integrated Care

16. Diabetes is a good example of a long-term health condition placing undue and increasing pressure on NHS resources. Effective health management means patients can live full, active lives, requiring minimal intervention from health and care services, whilst failure to appropriately manage the condition can lead to traumatic and costly procedures such as limb amputation.

17. Accenture conducted some preliminary analysis on diabetes trends in Wiltshire and found that between 2010 and 2025 the population living with diabetes is estimated to increase by 68%. Spend per registered patient with diabetes in the region has increased by 17% in the last five years, and projections show this will continue to increase. Wiltshire, clearly, is not unique: the challenge is a national one.

18. The provision of proactive health management is therefore urgently needed, and we believe that combining the following examples of integrated care and health management tools could lead to a dramatic improvement in patient outcomes and reduction in cost.

Examples of effective service integration of different actors

19. Integration from an acute perspective:

   Cambridge University Hospital (CUH), UK—Right patient, right place, right time across the care continuum

19.1 The problem: CUH wanted to reduce the length of stay (LOS) of patients to improve the patient throughput and experience, and reduce cost.\(^6\) This included preventing unnecessary delays to the discharge of patients with on-going care needs. A key challenge to achieving this was insufficient collaboration between the Trust and adult social care providers.

19.2 The solution: Accenture worked with CUH on a wide range of measures but the two most relevant for the Committee are the introduction of case management and the set-up of a single point of access to coordinate all discharge activities across several health and care providers.
   — Case managers (specially trained nurses) were introduced across wards in Medicine and Surgery. Patients had a dedicated case manager responsible for ensuring they were at the right place at the right time, speeding up the LOS and improving collaboration between health professionals, patients and their families.

\(^6\) Reduced length of stay (elective and non-elective) for patients requiring post-acute lower levels of care across all specialities; Reduced length of stay for patients (elective and non-elective) with no post-acute on-going care needs.
— A joint vision of integration between the Trust and community care providers was developed to minimise discharge delays. This led to the secondment of around 50 social care staff into an integrated CUH-based team. We also developed and agreed admission and discharge criteria for lower levels of care in line with global best practice guidance, profiled the existing community bed base and implemented process and pathways across acute and community providers.

19.3 The outcome: Implementation of this integrated care model reduced section 5 admissions by three days, led to LOS reduction of one day in surgery for patients with no on-going care needs and reduced outliers by 40%. Overall the benefit of case management led to reduction of 47,000 bed days over the course of one year, equating to around £5.5 million of cost savings. There were also significant improvements in patient experience, as well as in the satisfaction levels of healthcare staff.

20. Integration from a community perspective:

Large Cleveland-based research hospital system, US—Community-based patient navigators supporting chronically ill diabetes patients in the community

20.1 The problem: Research in the US found that unmanaged diabetes costs approximately 21% more than managed diabetes, in large part due to the higher levels of inpatient treatment.

20.2 The solution: Accenture worked with the hospital to implement a Patient Navigation Program (PNP). The PNP used non-medical “lay” staff in the community to help clinical staff to ensure chronically ill patients received continuous support outside the hospital setting. Patients were profiled and segmented and personalised interventions developed to target the particular needs of each group.

20.3 The Outcome: Patients are more compliant with their care plans after enrolment in the program, contributing to a decrease in no-show/cancellation. Whilst the annual cost to patients for unmanaged diabetes is $14,210, this was reduced to $11,744 after the introduction of the patient navigators.

Integration across different actors needs to be complemented with big data, analytics, technology and changing services

21. Integrating health and care services is a vital component to responding to the growing issue of chronic diseases. However, alone it is not sufficient to drive improvements in patient outcomes and required cost reductions. To achieve this, integration needs to be combined with evidence-based health management interventions that are supported by big data, technology and analytics.

22. Working with clinicians, nurses and healthcare providers, Accenture has developed a suite of interventions that have been proven to deliver improved patient and financial outcomes. These include:

22.1. Predictive analytics: spotting the most at risk patients and treating them before episodes become acute;

22.2 Case management and integrated discharge: improving cross-agency collaboration, increasing patient throughput and experience, and reducing cost;

22.3 Wellness management: Health coaching programmes engaging patients in positive motivation and behaviour modifications, and wellness screening and outreach campaigns; and

22.4 On-going education and monitoring; Telemonitoring and remote follow-up, for example using cutting edge TEKI technology, tailored to patients with long-term conditions.

23. There are multiple local and international examples of effective integration across health and care services which treat and manage long-term conditions. By addressing the barriers to implementing these models at scale, the NHS can deliver better outcomes for patients at significantly less cost.

13 May 2013

618 October 2012-March 2013 measured against October 2011-March 2012
619 CUH calculates bed days at a cost of £125/day. Using the Kings Fund figure of £250, the cost saving comes up to £12m annually.
621 For a short video detailing the innovative technology deployed in the Basque Country to connect clinicians and patients, including using patients’ televisions via TEKI technology, see http://www.accenture.com/us-en/Pages/success-basque-country-managing-increased-chronicity.aspx
Written evidence from the Association of Young People with ME (LTC 92)

1. Submission from the Association of Young People with ME (AYME) representing children and young people with ME/CFS.

2. The main issues faced by children and young people, particularly those who are long-term severely affected in summary are:
   (i) Long delays waiting for diagnosis, we regularly receive calls from parents whose children have just been diagnosed after three—five years, when is should be three—five months (NICE Guidance)
   (ii) GP’s unaware of referral process—leaving children without treatment, management and care.
   (iii) Parents are faced with providing twenty-four hour care, seven days a week often without support.
   (iv) No specialist paediatric hospital beds.
   (v) Much of the child population with ME/CFS has to rely on out of area referrals which, if moderate to severely affected, they can’t access.
   (vi) Poor communication between services that are provided unless the family is fortunate enough to be in an area with a specialist services (only 8 in England—cut from 11)
   (vii) Children and families are still faced with threats of safeguarding proceedings where there is no specialist support.
   (viii) 40% of those who finally get to a clinic have been misdiagnosed.

3. ME/CFS is the main cause of long-term school absence yet children are not able to access the care pathways, services and treatment provided to children with other long-term conditions.

4. Prognosis for children is vastly improved if diagnosed correctly and promptly—this is not happening.

5. Awareness in schools needs to be raised and education and health services need to work together to ensure the estimated 33,000 children and young people (1/100 children in secondary schools) are picked up early and the correct information provided. Where this has been implemented it has been effective but to date this only covers a minority of the estimated population.

16 May 2013

Written evidence from NHS Confederation (LTC 94)

1. Executive Summary

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— A growth in long-term and often multiple conditions poses a challenge to which the health service and society must respond. These changes are resulting in increased demand for care which is putting greater pressure on services such as accident and emergency and social care. The NHS will need to improve demand management and make care more person centred in order to meet the changing needs of people with long term conditions. This needs to be done in partnership with government and national bodies.

— To adapt to the changing requirements of people with long term conditions, we need services which look at all of an individual’s mental and physical needs. This sort of care will need to be more personalised, more joined up and provided more closely to people’s homes. People will also need to play a more active role in managing their own care and taking responsibility for their own health. We have been working to help ensure the NHS adapts to this growing challenge for some time.

— While the redesign of services must be locally driven to ensure it meets local needs, central Government and other national bodies have a key role to play in enabling care which is person centred, provided in or near their homes and supports self management. Our submission makes a number of recommendations to ensure better care for people with long term conditions:

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— The way in which funding flows through the system needs to be changed in order to incentivise joined up care, a greater focus on prevention and early intervention and the transfer of services into the community.

— Given the difficult financial situation, NHS organisations will need to consider what money the service currently has (for example in contingency funds) which can better be used to invest in redesigning services to meet the needs of those with long term conditions. There needs to be transparency about where the NHS is reinvesting existing funds, for example investing money from the emergency tariff into services aimed at managing demand.

— It is important that a collaborative, whole system approach is taken to commissioning the services needed to support people to manage their long term conditions. Clinical Commissioning Groups (CCGs) will need to be supported at a system level to work with local authority commissioners and NHS England. As part of this NHS England needs to provide clarity on how the specialist commissioning housed in NHS England will be part of this approach.
— Good leadership will be essential in ensuring a “whole system” approach to the challenges posed by long term conditions, both at a national and local level. Health and wellbeing boards should play a key role in joining up the system at a local level but they will need to be properly supported if they are to realise their full potential.

— To help manage demand we are calling for the introduction of services which aim to take a whole person and community approach to improving health, such as wellness services. To support this, NHS England should design a payment mechanism specifically to support coordinated services.

— Good child health is essential to the future health of the adult population and improving this needs to be a focus for the NHS, not least in relation to long term conditions. Improving child health would include making a preventative system a cross-government priority, as well effectively managing the transition to the new system where organisations have new responsibilities for commissioning care for children.

— Much is already being achieved on this agenda through innovative local NHS programmes. This submission contains a number of case studies which highlight the good work already being done by many of our members.

— However, if the health service is to truly meet the challenge posed by the rise in long-term conditions we need a fundamental shift in how we provide care to adopt these sort of initiatives at scale and pace. All parts of the NHS must respond to the challenge, a “whole system” approach will be vital to ensuring the health service meets the health needs of 21st century England.

2. Demographic Change and Prevention

2.1 The NHS is keeping people alive for longer. This is a success story for public health and the health service and it should be celebrated. But it does mean there is rapidly increasing demand from the growing number of people living with long term, multiple conditions, at a time when the NHS budget is flat in real terms. For example the population of over 65s is projected to grow by 50% over the next two decades.

2.2 The effect of lifestyle choices, including smoking, alcohol abuse and obesity, on public health and wellbeing have also increased pressures on the NHS. The cost for treating diseases associated with these lifestyle choices is estimated at a cumulative £17.9 billion each year—almost a fifth of the annual NHS budget.622 They have also led to an increase in some long-term conditions. For example, the NHS spends almost £10 billion each year on treating diabetes, of which 80% is spent on managing avoidable diabetic complications.623

2.3 The pressure resulting from these demographic changes is already apparent. The increased demand on accident and emergency services means patients are facing longer waiting times in many places. Demographic changes have also placed increased pressure on the social care system. Large numbers of people are experiencing delays in being transferred to the right sort of care. This can be distressing for patients and has a significant financial cost.

2.4 The NHS therefore needs to adapt. In this submission we argue adoption involves developing services in the community and organising care more around an individual’s needs. This will mean integrated care, including joining up NHS and social care. Equally the Government needs to find a long term solution to the funding problems which face social care. Significant long term changes are needed to improve the range and reach of social care so that people are supported to be as well and as independent as possible, for as long as they are able.

2.5 More needs to be done to manage the demand facing the NHS in order to lessen the pressures on the service. A key part of this will be greater investment in prevention and early intervention services. While local authorities now commission most public health services, there is still a role in this for the NHS. Significant initiatives led by both NHS providers and commissioners have strengthened early intervention efforts in areas such as psychiatric liaison, alcohol and falls prevention. However, our members have clearly stated this sort of work has often been driven by certain individuals and it is not yet something built into the NHS system. We must ensure these initiatives become the norm across the health service.

2.6 We are calling for the introduction of services which aim to take a whole person and community approach to improving health. These could for example include a combination of smoking cessation, weight management, or psychological well-being interventions such stress management. NHS organisations and local authorities should also work together through health and wellbeing boards to provide wellness services which take a whole person and community approach to improving health.

2.7 Our joint report with Altogether Better, an organisation which creates and supports community champions, Community health champions: creating new relationships with patients and communities,624 highlights one approach to community care where voluntary “champions” receive training to help their friends,

624 NHS Confederation, Community health champions: creating new relationships with patients and communities, June 2012.
families, neighbours, communities and work colleagues lead healthier lives. Evidence from this work shows an increase in confidence, improvements in physical and mental health and lifestyle, and increased knowledge of health issues. It has also been shown to have a positive return on investment.

2.8 The NHS also needs to maximise the opportunities healthcare professionals have with individuals and communities to improve their health and well-being (the so-called “every contact counts” approach). We recommend that:

— To support a whole person and community approach, NHS England should design a payment mechanism specifically to support coordinated services.625
— Commissioners should consider how their service specifications in providers’ contracts support the “every contact counts” approach...

2.9 Good child health is essential to the future health of the adult population. However, England has one of the highest mortality rates in Europe for those aged 0 to 14. The level of obesity among children remains high, with 19% of children aged ten to 11 years defined as obese, and continues to rise. Planned care for long term conditions “gives cause for concern” with many preventable asthma admissions and poor diabetic control.626

Improving child health would include making a preventative system a cross-government priority. Our report Children and young people’s health and wellbeing in changing times627 sets out in more detail the recommendations we have for improving child health.

2.10 For young people with long term conditions, the transition to adult health services is a difficult time. Transition needs to be built into care pathways as a process rather than a discrete event. Local leadership on improving transition is also needed, for example, through a designated transition lead in each local area and clinical champions within provider organisations.

2.11 Draft legislation on reform of provision for children and young people with Special Educational Needs includes provision for joint Education, Health and Care plans to secure personalised services across health, education and other relevant areas for children with a high level of need. For this policy to work well, all parties will need to understand the potential benefits of such policies and implement them in ways designed to secure these benefits. We were therefore pleased that pathfinders for this policy were extended, as it had been challenging for the NHS to engage with them during a period when PCTs were closing and CCGs becoming established.

3. INTEGRATING CARE AROUND THE NEEDS OF THE INDIVIDUAL

3.1 People with long term conditions interact with the health service in a different way than those with a single episode of care, such as a broken leg. Those with long term conditions will have more frequent contact with the NHS, often interacting with multiple parts of the system over a sustained period of time. Given many long term conditions cannot be “cured”, the focus will be more on managing the condition and helping people to stay as well as possible for as long as possible.

3.2 This all means that the health service needs to interact in a different way with patients than in the past and a key part of this will be to ensure that the various parts of the system are joined up to ensure that the patients’ interactions with the system (or “care pathway”) are properly coordinated. This approach needs to make better use of resources and improve people’s experiences by delivering the right care in the right place. This greater integration of care needs to involve not just NHS services but also local authority provision, particularly social care. It also means engaging better with patients as people with an active role to play in improving and maintaining their own health, not simply passive recipients of care. We welcome the narrative for integrated care recently set out by National Voices, which is helpful in setting out what is meant by the term integration628 and the recent announcement by the Government on integration “pioneer” sites.

3.3 A range of models have been developed by local leaders to fit local needs. The North West London Integrated Care pilot which we outline later in this submission is one example of the NHS implementing an innovative model of care which meets the needs of those with long term conditions. However, more needs to be done to ensure that widespread adoption of these models. Our previous joint submission with ADASS and the Local Government Association to the Committee’s public expenditure inquiry highlighted recommendations for ensuring this is the case. To help ensure integrated care is adopted at scale and pace our recommendations include:

— The way funding moves through the system needs to be reformed. National bodies need to ensure the mechanism used to pay NHS organisations for activity (the tariff)is reformed to encourage more joint work between organisations. Government also needs to streamline the complex funding mechanism across health and social care which prevent the two sectors from sharing savings made from joint work.

625 NHS Confederation, From illness to wellness, Oct 2011.
626 Wolfe et al, Improving child health services in the UK: insights from Europe and their implications for the NHS reforms, BMJ 2011; 342:d1277
627 NHS Confederation, Children and young people’s health and wellbeing in changing times, January 2013
4.3 With central Government funding unlikely to significantly increase in coming years, the NHS will need to make best use of the money already available to it in order to invest in redesigning services. This could mean redistributing funds as done in the below example of an integrated care model, or considering using some of the money currently held in contingency funds. We need transparency around the reinvestment of existing funds, as done in the below example of an integrated care model, or considering using some of the money already available to it in order to invest in redesigning services. This could mean redistributing funds as done in the below example of an integrated care model, or considering using some of the money currently held in contingency funds. We need transparency around the reinvestment of existing funds.
savings such as from the ring fenced 2% of clinical commissioning groups budgets or 30% management tariff into demand management. For example, the North West London integrated care pilot, whose start up costs were funded by savings from the marginal tariff, has already begun to reduce admissions to accident and emergency departments, specifically for older people with diabetes.

**Case Study—The North West London Integrated Care Pilot (ICP)**

The North West London Integrated Care Pilot (ICP) was launched in June 2011 and brings together more than 100 general practices, two acute care trusts, five primary care trusts, two mental health care trusts, three community health trusts, five local authorities, and two voluntary sector organizations (Age UK and Diabetes UK) to improve the coordination of care for a pilot population of 550,000 people.

The ICP was developed in response to variations in the quality of care and a rising deficit across the local health economy. The clinicians involved decided two areas of focus for integrated care: people older than 75 years and those with diabetes. These groups were experiencing a high level of avoidable admissions and variable care, there was known best practice and improved outcomes would be measureable.

The ICP developed a unique model of clinicians working together in multi-disciplinary groups within a multi-disciplinary system. The multi-disciplinary group (MDG) risk stratified the patients identified for the pilot, developed shared protocols for care across organisations, discussed these protocols and developed care plans with patients, mapped available care and addressed gaps in provision, introduced case conferences for patients with particularly complex needs or significant problems, and reviewed overall performance of the pilot.

£7 million investment was provided by London SHA channelling the funds from the 30% marginal tariff on “excess” emergency admissions to hospital. This provided for an operational team, an information tool (to support risk stratification, care planning, sharing of medical information and evaluation), care coordination and incentive for providers to save.

Some benefits have been seen relatively early in the pilot, though it is anticipated the full benefits would become apparent over a five–10 year timescale. Based on analysis of the impact to date, the ICP hopes to reduce emergency admissions for people over 75 with diabetes by 10%. Patients are also experiencing better coordinated care across different providers. The aspiration for the pilot is to scale up to the whole local population, focusing on the 20% that drive 80% of cost.

4.4 There is widespread agreement that more care in people’s homes and communities, wherever clinically appropriate, is the right approach and can more effectively help support those with long-term conditions. Shifting care away from an acute setting and into the community was the second most frequently chosen priority area for respondents to the NHS Confederation’s 2012 members survey at 63%. A survey published by the Department of Health in 2012 found that 66% of the members of the public polled in the survey agreed that moving services into the community can raise standards.

4.5 As outlined in our 2013 briefing on the role for community healthcare in transforming local care, the community health sector is already driving the transformation of local care systems. Innovative community healthcare providers are enabling people to stay healthy and independent and avoid crises that lead to unplanned hospital admissions. Community services are moving the focus away from traditional models of healthcare in acute settings to nurse-led rehabilitation in, or closer to, peoples’ homes, the provision of “hospital at home” services such as diagnostics and chemotherapy, and community-based end of life care. Central to the community health model are prevention, early intervention and enabling timely discharge or transfer from hospital to improve recovery. The below case study highlights the strength of a community approach to a long term condition.

**Case Study—Community Service for Respiratory Disease**

A community-based respiratory team was set up in Hammersmith and Fulham to improve care for people with chronic obstructive pulmonary disease (COPD). The service put in place specialist support to primary care services, workplace-based training, a community based rehabilitation programme and community clinics. It also supports patients after their discharge from hospital and helped them self-manage their care. Benefits from this include reduced first and follow-up appointments, saving £170,000, 19% reduction in admission to hospital for COPD and a 66 per reduction in readmissions.

4.6 More needs to be done to achieve the scale and pace of change in order to meet the challenges of a long term condition. The Government and national bodies needs to examine how the current way NHS organisations are paid for their activity can be reformed to incentivise shifting more care into the community. The NHS also needs to redesign the way we currently plan and provide services, in order to shift more care from a hospital setting into the community and people’s own homes. Such an approach will improve the quality of care provided to patients with long term conditions and has the potential to save money.

631 Department of Health, Public perceptions of the NHS and social care, 2012
632 NHS Confederation, Transforming local care: Community services rise to the challenge, March 2013.
633 NHS Confederation, Realising the benefits of community health services, June 2012.
4.7 It is important that a collaborative, whole system approach is taken to commissioning the services needed to support people to manage their long term conditions. Clinical Commissioning Groups (CCGs) cannot do this alone. They need to be supported at a system level to work with local authority commissioners and NHS England. We remain concerned about the lack of clarity around how CCGs will work jointly with specialist commissioning housed in NHS England. We urge NHS England to set its plans out as a matter of urgency.

4.8 Equally secondary providers and commissioners will need to work more closely together to play an active role in facilitating care in community settings and enabling people with long-term conditions to self manage. In addition, commissioners will need to demonstrate that the way they are commissioning achieves good outcomes for patients. Good evidence which demonstrates that care in community settings improves patient outcomes and saves money in the long run will therefore be essential.

4.9 In the face of potentially unpopular decisions, health and wellbeing boards have an important advocacy role in making the case for change, especially where service reconfiguration and service closure is involved. However, though significant advances have been made at this early stage of the Boards’ development, there remain considerable challenges to realising this potential. Board members will need strong communication and political skills. In addition, most boards already have a partnership of shared respect and understanding, but to effectively support service redesign they will need to go beyond this to become a cohesive, unified body in which overall strategic priorities are put above personal or organisational interests.

5. THE INTERACTION BETWEEN MENTAL HEALTH CONDITIONS AND LONG-TERM PHYSICAL HEALTH CONDITIONS

5.1 People with long-term physical health conditions will often have psychological and emotional needs resulting from illness-related symptoms, disability associated with the physical illness, or the impact of living with more than one physical condition at any time. For example, depression is at least twice as common in people with diabetes, with an estimated 41% of people with diabetes having poor psychological wellbeing, and many with psychological needs that do not meet the criteria for a formal diagnosis. Evidence shows that depression exacerbates the complications and adverse consequences of diabetes, in part because patients have difficulties with managing their diabetes.

5.2 The NHS therefore needs to ensure that services are designed and delivered around the needs of an individual as a whole. It is important the mental health and the rest of the system work in a joined up way, particularly in developing and delivering integrated care for people with long term conditions.

5.3 Failing to recognise the link has economic costs—healthcare costs are higher and productivity is lower due to reduced work performance, increased absenteeism and withdrawal from the labour force. For example, in the UK, individuals with co-morbid depression and diabetes are four times more likely to have difficulties in self-managing their health and seven times more likely to have days off work compared to people with diabetes alone. Evidence shows that addressing psychological needs of diabetic people through a range of interventions such as cognitive behavioural therapy (CBT) or anti-depressant therapy include: reduced psychological distress and anxiety; improved mood and quality of life; improved relationships with health professionals and significant others; and improved eating-related behaviours such as purging and body image symptoms

5.4 We believe there is considerable potential to improve quality of life and quality of care, and to generate service efficiencies and cost savings in this area. Our Mental Health Network has published a document which sets out the interactions between a number of physical and mental long term conditions. The document details a range of case studies which shows the work a large number of NHS organisations are doing to address both the mental and physical health needs of patients with long term conditions, and the benefits this work has.

5.5 The report highlights that many individuals do not receive care that addresses both their physical and psychological needs. More needs to be done to recognise this and treat the whole person, rather than specific conditions. The report argues for a shift in the way we provide care to address this, and in particular more emphasis put on the self management of long term conditions. It also echoes the recommendation made by the Royal College of General Practitioners and the Royal College of Psychiatry for all primary care staff to have psychological awareness training in order to provide whole person care.

ABOUT US

The NHS Confederation represents all types of organisations that commission and provide NHS services. It is the only membership body to bring together and speak on behalf of the whole of the NHS.

20 May 2013

634 Investing in emotion and psychological wellbeing for patients with long-term conditions, NHS Confederation’s Mental Health Network(MHN), April 2012.
635 ibid.
1. **INTRODUCTION TO ROBERT BOSCH**

   1.1 Robert Bosch Healthcare offers a wide ranging portfolio of care products for chronically ill patients and the elderly which helps to bring significant quality, efficiency and financial gains to the UK healthcare sector. Our aim is to help people with long term conditions remain in their own homes and out of hospital wherever possible.

   1.2 Bosch’s telehealth spectrum ranges from in-home patient terminals to comprehensive software allowing healthcare professionals to efficiently evaluate risk-stratified data coming from the patient terminals and other connected devices. Bosch Telehealth strives to improve the care and management of patients with long-term conditions through systematic patient education, behaviour modification support, daily monitoring of symptoms and vital signs and patient engagement techniques. The result is that health professionals are able to provide a higher quality of care for patients with chronic conditions, patients lead happier and healthier lives, and the cost of healthcare is reduced for funders. Robert Bosch Healthcare Systems, Inc. is a fully-owned subsidiary of the Bosch Group.

   1.3 The Bosch Group is a leading global supplier of technology and services and is represented in over 60 countries. The company was set up in Stuttgart in 1886 by Robert Bosch (1861–1942) as a “Workshop for Precision Mechanics and Electrical Engineering.” The special ownership structure of Robert Bosch GmbH guarantees the entrepreneurial freedom of the Bosch Group, making it possible for the company to plan over the long term and to undertake significant up-front investments in the safeguarding of its future. Ninety-two% of the share capital of Robert Bosch GmbH is held by Robert Bosch Stiftung GmbH, a charitable foundation.

2. **SUBMISSION ON BEHALF OF BOSCH HEALTHCARE UK**

   2.1 The respected health think-tank, 2020health, recently published the findings of its own study of a telehealth hub pilot in Yorkshire. It found that telehealth-enabled care co-ordination can reduce hospital admissions, provide care at home and improve patient outcomes. It noted that for every 100 patients using technology, 10 hospital admissions are averted each month—that’s up to £2,000 saved per averted admission, representing a return on investment of 48%.  

   2.2 The Department of Health (DH) believes that at least three million people with long term conditions and/or social care needs could benefit from the use of assistive technologies and telehealth services.

   2.3 Implemented effectively these technologies can alleviate pressure on long term NHS and social care costs and improve people’s quality of life through better self-care in the home setting.

   2.4. Bosch believes that the key to achieving this goal is a more integrated approach to health and social care. Bosch supports NICE’s new oversight role on social care and welcomes the opportunity to make a submission to the Health Select Committee on the management of long term conditions. For technology to work, it must be embedded in care pathways that are designed for patients with long term conditions. This means managing their conditions across the continuum of care—at home, in the community and in clinical settings.

   2.5 Our experience has told us that:
      — Technology is a tool to enhance a robust coordination strategy.
      — Successful technological deployment requires many stakeholders who must be willing—and have incentives—to participate in the process.
      — Technology must be engaging and easy to use in order to encourage self-management and adherence.
      It should create a positive user experience for clinicians and patients.

   2.6 This is particularly relevant to NICE’s proposed guidance on medicines management in home-based settings and Reablement. Bosch, whose systems support medication compliance, believes that this proposed guidance will play a significant role in managing long-term conditions.

3. **3MILLIONLIVES**

   3.1 The 3millionlives campaign was launched on the back of the initial results from the Whole Systems Demonstrator (WSD) Project with the goal of bringing technology-enabled integrated care to 3 million people in the UK by 2015.

   3.2 A key part of this strategy is the first Mandate between the DH and NHS England, published in November 2012, setting out the requirements for the health service in forthcoming years.

   3.3 The NHS Mandate is structured around five key areas where the Government expects the NHS England to make improvements:
      — preventing people from dying prematurely;
      — enhancing quality of life for people with long-term conditions;

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4. THE WHOLE SYSTEM DEMONSTRATOR AND HOW BOSCH IS DIFFERENT

4.1 Technology has a vital role to play in meeting these intrinsically linked objectives. The second stage findings of the WSD have unfortunately “muddied the waters” in terms of moving the technology agenda forward.

4.2 Bosch was disappointed with the second stage results of the WSD and its apparent limited effect on quality of life and psychological outcomes. Bosch telehealth systems have demonstrated, in more than 40 publications, that its content-driven telehealth intervention supports integrated care and consistently produces significant cost savings in addition to improvement in both clinical outcomes and the quality of care.637

4.3. Bosch Healthcare’s Health Buddy System (HBS) was not part of the WSD project and provides a more integrated solution than the telehealth interventions used in the WSD. Whilst many systems focus on vital signs monitoring, Bosch systems utilise more extensive education to support improved patient self-management, positive reinforcement of behaviour change which is personalised to the patient.

4.4. Whilst a significant study for telehealth in the UK, there are several mitigating factors that need to be considered when reviewing the results of the WSD. For example, telehealth devices and monitoring systems varied amongst the study sites and there were inconsistencies in describing exactly what the telehealth interventions were. Crucially none of the systems used provided support for increased efficiency and effectiveness of clinician workflow or supported improved patient self-management.

4.5. These latest results are understandably influencing the decisions of commissioners who are currently in the process of shaping the composition of future service delivery.

5. EVIDENCE

5.1 With an ageing population on the one hand and ongoing budget restrictions on the other, the results have called into perspective an ever-more-urgent need to look at how to create a sustainable delivery model for the future.

5.2 Therefore UK health and social care services must also look abroad for the evidence base to support a more integrated approach to managing long term conditions. To take the example of a study from the USA Medicare system (which has parallels with the NHS) that focussed on Congestive Heart Failure (one of this Inquiry’s terms of reference) Bosch found significant reduced mortality for patients through the use of its telehealth in combination with care coordination:

— Analysis of data derived from the Medicare Care Management for High Cost Beneficiaries (CMHCB) Demonstration project showed that care coordination supported by Bosch Healthcare’s content-driven remote patient monitoring system resulted in a 57% lower mortality risk for heart failure patients after three years.
— These findings were presented at the American Heart Association 2012 Scientific Sessions Meeting in Los Angeles on 7th November 2012.
— In 2010, costs in the USA, associated with heart failure (HF) were estimated to be $34.4 billion annually (it is estimated that the total annual cost of heart failure to the NHS is around 2% of the total NHS budget.638)
— In 2006, Medicare beneficiaries with HF accounted for 37% of all Medicare spending and 50% of all inpatient hospital costs.

5.3 Developing strategies to reduce readmission rates and improve outcomes for patients with HF has become a national health priority in the United States, as it has in other developed countries.

5.4 Data for 623 matched pairs of Medicare HF beneficiaries were analysed. The results showed that care management combined with the Health Buddy System was associated with a 25% reduction in all-cause mortality risk in beneficiaries with HF, who were offered the programme and a 57% reduction in mortality risk for those HF beneficiaries who actively participated in the programme compared to the control studies.

5.5 Empowering patients does not only statistically influence health outcomes but has associated cost and social benefits too. Self-management helps reduce the cost burden on services through reducing the number of staff required per patient and in social terms the education component, common to many assistive technologies, greatly increases health literacy. The long term benefits of increased health literacy are exponential.

5.6 These “on the ground” results are, more often than not, the product of integrated delivery systems being put into practice through healthcare and industry partnerships that handle populations with high numbers of people with chronic conditions.

5.7 For technology to work, it must be embedded in care pathways that are designed for patients with long term conditions. It should comprise of a range of interventions—including coaching and telecare.

6. **Conclusion**

6.1 Bosch’s studies have demonstrated that, through giving patients an active role in their treatment, they can significantly influence their own health outcomes. Bosch believes that this will be vital to the future strategy of managing long term conditions.

— There must be a discussion on wider care coordination to look at where technology fits in—as opposed to the other way round.

— Patients with long term conditions will be one of the most significant cost drivers for the NHS in future. Empowering patients to manage their conditions well from home (by increasing health literacy) will be at the centre of cost management.

— Bosch believes the best use of technology is when it is built into an integrated care structure that has been set up within an existing delivery system—integral to this is a comprehensive link between health and social care services.

— Our considerable experience in this area demonstrates that it is critical to install and maintain a consistent approach to the use of assistive technologies, best practice and implementation across the study groups—Academic Health Science Networks will have an important role to play in sharing best practice and supporting the health industry.

— Assistive technologies work best when there is strong and sustained clinical and administrative leadership and support driving their use—properly incentivising commissioners to deploy it is integral.

20 May 2013

**Written evidence from the ME Trust (LTC 97)**

**CHRONIC FATIGUE SYNDROME/MYALGIC ENCEPHALOMYELITIS CFS/ME**

— CFS/ME is a disease of unknown origin. It affects an estimated 0.2–2.0% of the population.

— Diagnosis can take years—and misdiagnosis is common.

— People with CFS/ME fall through the existing care nets.

— The severely affected are particularly misunderstood, unsupported and even neglected.

— If fortunate to have the correct care, a significant proportion improve or recover—even after very long term severe illness.

— Lack of NHS Commissioning and NICE guidelines can prevent patients receiving funding for appropriate care.

1. The World Health Organisation (WHO) classifies M.E. as a neurological disease and lists it as an alternative term for post viral fatigue syndrome. CFS is a condition that causes long-term fatigue and other symptoms which are not caused by any other known medical condition. Symptoms can vary and until there are improvements in diagnosis the umbrella term CFS/ME, which was suggested by the Working Group to the Chief Medical Officer, is generally used.

2. National Institute for Health and Clinical Excellence (NICE) defines CFS/ME as a condition where healthy individuals experience severe fatigue following mental or physical activity, and can be triggered by an infection.

3. CFS/ME is a disease of unknown origin with a wide spectrum of symptoms and severity. Studies show it may affect an estimated 0.2–2.0% of the population but there is a lack of epidemiological data in the UK, so numbers are uncertain. The most severely affected can be bed-bound and in pain for years. There is no scientific medical cure. The physical symptoms may ruin lives and can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions.

4. Patients able to access the very limited NHS specialist services have been ill on average for three—four years before being diagnosed and are unwell for an average of 6.3 years.6.99

5. People referred to the limited NHS specialist services are considered to be the “tip of an iceberg” as the majority of the severely affected, the bed-bound or house-bound, are unable to access these services and are therefore generally excluded from data.

Dr Mike Cheshire, Vice President of the Royal College of Physicians 2007–10, candidly states: “Sadly CFS/ME does tend to fall through the net, with many patients receiving neither the diagnosis, support nor the information they need. It is difficult to diagnose, many doctors still doubt that it exists and therefore failure to recognise it is common.”

6.99 Figures collated by the CFS/ME National Outcomes Database team at Bristol University
Although cost effective help could be provided for patients with CFS/ME, the Government’s Chief Medical Officer’s report,640 NICE guidance641 and parliamentary enquiry642 all suggest that few patients have access to appropriate care and support. The CMO report, NICE, parliamentary enquiry, and numerous patient surveys, highlight the urgent and unmet needs of the severely affected.

6. NICE guidelines state the severely affected should be referred immediately to a specialist. Few receive such a referral/support. Provision of specialist services in this country is almost non-existent and there is scant provision for home visits or support for the bed-bound or house-bound. CFS/ME is typically excluded from private health insurance (PHI).

7. ME Trust Chair of Trustees, Hannah Clifton, had ME for 12 years and fell through the care net. She recovered completely after finally accessing inter-disciplinary care tailored to her individual needs by Burrswood Hospital, a Charity and independent hospital in Kent.

Hannah is a former City of London Solicitor. She spent most of the 12 years of her illness bedbound and in pain. Throughout those years, she was told by a succession of GPs that no hospital bed was available for her on the NHS. She was given only 13 weeks of social services support and no other specialist help or support at home. Her “probable” diagnosis of CFS/ME was confirmed after years of illness. In May 2008, her GP’s prognosis was that she “probably would not get better.” That month she travelled bedbound in a campervan to Burrswood. Four weeks later she was walking and pain free.

In June 2011, Hannah Clifton founded the M.E. Trust. The vision of the Trust is that all people with CFS/ME have access to the best resources for diagnosis, treatment and care to enable early and full recovery. That year, Burrswood Hospital also appointed her as a Volunteer Patient Liaison on CFS/ME to the Hospital.

Hannah has been privileged to meet with numerous patients with CFS/ME at Burrswood Hospital including the following:

— A lady from the North of England who arrived by campervan in Spring 2012, ill for four years and wheelchair bound. She had raised funds through family and friends for a three week stay. The Trust funded a fourth week. She began walking again on that 4th week and is back at work part time.

— A person from the West Country, 18 years bed-bound, who travelled to the hospital for 7.5 hours on a mattress in a hire care. She began walking on the fifth week of her stay and has just holidayed in the Canaries.

— A patient from the North of England, severely affected for 23 years, now walking again after the hospital discovered she in fact had Lyme disease.

— A lady from the East of England who spent 18 months in a pitch black room bedbound with severe neurological damage. On the fifth week of her stay, she began to walk again and could enjoy daylight. She is now able to sit for 7 hours and goes out shopping unaided.

A two year study by Kent University on CFS/ME care at Burrswood Hospital has very encouraging mid-term results.643 The final report is expected to be published in September 2013.

8. The M.E. Trust is working in association with Burrswood Hospital to bring the highest standard of specialist care to all with CFS/ME as part of our vision to transform the lives of people with the illness. We aim to support a Centre of Excellence at Burrswood—the first specialist centre of its kind in the UK. We very much hope Burrswood Hospital will be a referral centre for, and to work with, the NHS. Our ambition is that Burrswood Hospital will be a model for the provision of CFS/ME in-patient care nationally with the intention of developing another centre, possibly in the North of England.

Our Patron, Dr Mike Cheshire states: “CFS/ME is difficult to diagnose, and difficult for the doctor and the patient to manage. Burrswood Hospital will provide the opportunity to confirm the diagnosis and have treatment tailored to the patient’s individual needs”.

Patients are often excluded from obtaining the life transforming care that is needed due to lack of understanding and of funding. It is not unusual for patients to have waited 10 years or more for much needed specialist care before finally hearing about Burrswood. They often lack the means to pay and NHS Commissioners often refuse to make a referral. Patients who are able to fund stays at Burrswood Hospital use a mixture of private means [family and friends donations] or benefit from charitable funds provided by Burrswood. Most patients are not in a position to raise funds for other than a short term respite stay. Hannah paid for her stay—originally three weeks, but extended by agreement with the care team at Burrswood Hospital, to three months, using the sale proceeds of her home, as her PCT declined to reimburse the cost. NHS referrals to Burrswood Hospital do occur but are not common.

The cost of an inpatient stay at Burrswood Hospital compares favourably with NHS rates. Burrswood charges approximately £300 per night for a single en-suite bedroom including all food, medical visits, treatment, nursing and clinical care, compared with a cost of £250–300 for a hospital bed in an NHS Hospital.

9. Burrswood Hospital is a 40 bed independent hospital. It offers adults the highest levels of evidence based interdisciplinary clinical and compassionate nursing care to ensure that patients achieve the best possible outcomes. In-patient medical care is provided by an experienced resident medical team who are available 24 hours a day. Senior Physician Dr Paul Worthley has 20 years’ experience of helping people with the illness—extraordinarily rich expertise in a field not taught in medical schools. Skilled nursing care, counselling, physiotherapy, input from chaplains and support staff are all available.

At all times Burrswood Hospital’s individually tailored approach ensures that each patient’s own specific needs and requirements are met. The available physical and psychological energy levels of each individual patient determine the programme of each person’s stay. Lengths of therapeutic sessions are paced, as appropriate, in agreement with the patient. Rooms are specially furnished and fitted out so as to address the noise and light sensitive concerns of CFS/ME patients, and the whole Hospital service provides an appropriate setting to improve recovery.

10. Dr Cheshire adds: “CFS/ME is difficult to diagnose, and difficult for the doctor and the patient to manage. The Centre at Burrswood will provide the opportunity to confirm the diagnosis and have treatment tailored to the patient’s individual needs.”

11. Burrswood cannot provide a medical cure for CFS/ME—there is none, but it can provide desperately lacking “whole-person” individually tailored patient care. Many who receive that care are able to manage their illness better, report significant improvement in symptoms and recover to lead full lives again—despite years of long term severe illness. We are passionate that this pioneering care be available to all who need it. People falling through the existing care net in this country, and not receiving support in accordance with NICE guidance, could be receiving the help and support they needed if funding support was made available.

12. Patrick Luyten UCL Senior Lecturer; Asst Prof Leuven University says:

“There is a desperate lack of provision for people with CFS/ME both in this country and worldwide. This landmark Centre promises to provide ground patient-centred specialist care, and could be at the vanguard of much needed change internationally”.

6 June 2013

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644 http://www.burrswood.org.uk/sites/default/files/Burrswood%20Poster%20interim%20June%202012%20(2)