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NHS Continuing Care

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The Health Committee

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Footnotes

In the footnotes of this Report, references to oral evidence are indicated by 'Q' followed by the question number. Written evidence is cited by reference to Volume II of this Report, in the form 'Ev' followed by the page number.

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Summary

It is estimated that as many as one in three women and one in five men will eventually require long term residential care. While in the past, people requiring long term residential care were likely to be cared for in NHS long stay community hospitals, entirely funded by the NHS, the number of hospitals providing such care has dwindled over the past twenty years. In many respects this has been a positive change, enabling more people to be cared for in their own homes. However, it has also meant that increasing numbers of people who would previously have received free NHS care, are now cared for in private, fee-paying residential or nursing homes. How this care should be funded has been a contentious issue for over a decade.

Current arrangements for funding long term care are beset with complexity, and lack of clear Government guidance has led to widespread variations across the country. The artificial barriers between health and social care lie at the heart of the problems surrounding access to continuing care funding. It will be impossible to resolve these problems without first establishing a fully integrated health and social care system. We have therefore recommended, as this Committee and its predecessor Committees have done on numerous previous occasions, that the Government removes the structural division between health and social care.

Recognising that this radical reorganisation will take time, we have also made a number of recommendations for the Government's forthcoming national framework for NHS continuing care. First and foremost, the framework must include the establishment of a long-overdue single set of national eligibility criteria for continuing care to end the 'postcode lottery' in access to continuing care funding. Rather than solely focusing on physical health, these criteria must also take full account of psychological and mental health needs. They should also be rigorously reviewed to ensure they are compliant with the tests established by the Coughlan judgement.

It is also crucial that the Government underpins its national eligibility criteria with the establishment of a national standard assessment methodology to ensure assessments against national criteria are carried out robustly and uniformly across the country.

There are currently two parallel systems for funding NHS continuing care and for funding nursing care for those who do not qualify for fully funded NHS continuing care, and overlap between these is causing major confusion. We have therefore recommended that these two systems are integrated.

Very worryingly, our evidence suggested that the current systems reward dependency rather than encouraging care staff to help increase and maintain patients' independence. We have therefore recommended that the system for funding continuing care and nursing care is redesigned, so that the system has inbuilt incentives which reward high quality care and promote rehabilitation and independence.

1 Introduction

1. As one in three women in Britain, and one in five men, will eventually need long term care, the funding of such care is an issue that is likely to touch most people's lives in one way or another.¹ Announcing the establishment of the Royal Commission on Long Term Care for the Elderly in 1997, the then Secretary of State for Health explained the reasons for its appointment to the House:

People are entitled to security and dignity in their old age, so we must find a way in which to fund long term care which is fair and affordable both for the individual and for the taxpayer.²

2. Responding to the Royal Commission in July 2000, the Government again reiterated its pledge to modernise the present system of care, which it described as “confusing, unfair and unresponsive to people's needs”.³ However, over six years after the Royal Commission reported, and nearly ten years after concerns were first raised by a predecessor Health Committee about NHS continuing care funding, elderly people, as well as those with learning difficulties and others requiring ongoing care, still find themselves subject to a bewildering funding system which is little understood even by those who administer it, and which few patients or carers would describe as “fair”, or as guaranteeing their “security and dignity”.

What is NHS continuing care?

3. The term NHS continuing care means fully funded care for people who do not require care in an NHS acute hospital, but who nevertheless require a high degree of ongoing health care. Anybody can qualify for NHS continuing care funding if their needs satisfy eligibility criteria, although the largest group of people who receive continuing care funding are elderly people. Continuing care funding is intended to cover the entire costs of care, including all medical care, nursing care, personal care, living costs and accommodation costs, the same as if their care was being provided in an NHS hospital.

4. Eligibility for continuing care funding is currently established with reference to criteria introduced by the Department of Health in 1995.⁴ The criteria relate to the complexity, intensity or unpredictability of a patient's healthcare needs, requiring the regular supervision of a consultant, specialist nurse or other member of the NHS multidisciplinary team. From 1995 onwards, individual Health Authorities were each required to develop local policies and eligibility criteria for continuing care funding within this general framework.

¹ Royal Commission on Long Term Care, *With Respect to Old Age: Long Term Care – Rights and Responsibilities – Research Volume I*, March 1999, Chapter 1 para 28

² HC Deb, 4 December 1997, cols 489-499

³ Department of Health, *The NHS Plan – the Government Response to the Royal Commission on Long Term Care*, Cm 4818, para 1.4, July 2000

⁴ Department of Health, *NHS Responsibilities for meeting continuing health care needs*, HSG(95)8, 1995

Background to NHS continuing care

5. The last two decades have witnessed significant changes in the way in which long term care is provided. The closure over a number of years of NHS long-stay wards and community hospitals which had previously cared for people who did not need the high level of care provided by an acute hospital, but who were unable to care for themselves in their own homes, has meant that a growing number of older people are being cared for either in residential or nursing homes, or in their own homes.

6. NHS continuing care eligibility criteria were designed to identify and provide free care only to those who had a high level of need for ongoing *health* care, as distinct from supportive help with the daily activities of personal care, such as washing, dressing and eating. Thus, the majority of elderly people being cared for on a long term basis in residential or nursing homes, or by carers in their own homes, were not eligible for continuing care funding. Instead, as their care was deemed to be ‘social’, means-tested funding was provided by local authorities, with the better off service users paying the full costs of their care.

7. However, in practice the distinction between health and social care is very blurred. The Care Standards Act 2000 arguably added to the blurring of boundaries by abolishing the statutory distinction between nursing homes and residential homes; retaining some requirements for care homes providing nursing; and bringing them within a social care regulatory regime.⁵

8. Significant public concern about whether it was fair for such people to have to fund all or part of their care in residential or nursing homes - when ten years previously they might have received it free in an NHS long-stay hospital - resulted in the establishment of the Royal Commission on Long Term Care for the Elderly. The Royal Commission recommended that the costs of long term care should distinguish between living costs, housing costs and personal care costs, and argued that all nursing care, and all ‘personal care’, defined as care which involves touching the patient, such as help with washing and dressing, should be provided free and from general taxation. People would remain responsible for the living and housing cost components, and means-testing would apply.⁶

9. In its response to the Royal Commission on Long Term Care for the Elderly, the Government rejected its central call for personal care to be provided free of charge. However, it did decide to address anomalies in the system whereby some people in nursing homes were paying for the costs of their nursing care as part of their fees, which they would have got free in hospital or in the community.⁷ The Registered Nursing Care Contribution (RNCC) system was introduced in October 2001⁸.

⁵ For the purposes of clarity we use the terms nursing and residential homes to make a distinction between those registered to provide nursing and those registered to provide personal care only.

⁶ Royal Commission on Long Term Care, *With Respect to Old Age: Long Term Care – Rights and Responsibilities*, Cm 4191 – I, March 1999

⁷ Department of Health, *The NHS Plan*, Cm 4818 – I, July 2000, para 15.18 – 15.20

⁸ The RNCC was introduced from 2001 for self-funders, and from April 2003 for existing and future (nursing) care home residents who receive council support.

10. Ever since the introduction of eligibility criteria for NHS continuing health care there have been problems. These difficulties have arisen around the interpretation and application of criteria, and whether those criteria have been too restrictive in practice. Individual challenges have raised general principles and questions, and this has been increasingly evident in the involvement of the NHS Ombudsman, and of judicial review. A key development in continuing care funding was the 1999 Court of Appeal Coughlan judgement, in which Pamela Coughlan, who had significant ongoing health care needs sustained in a road traffic accident but had been denied NHS continuing care funding, successfully sued her local Health Authority. The judgement established that “if the needs of the patient were primarily health needs, the Health Authority was as a matter of law responsible”, and the NHS should pay for the whole package of care. Following on from this the Government told all Health Authorities to ensure their continuing care policies and eligibility criteria were ‘Coughlan compliant’.

11. Despite this, patients and carers continued to report problems in attaining appropriate funding for their ongoing care, and in February 2003, the Health Services Ombudsman presented a special report to Parliament concluding that Health Authorities were using over-restrictive local criteria which were not properly in line with Department of Health guidance nor with the Coughlan judgment, and that as a result people had been unjustly denied continuing care funding.⁹ Concerned that the problem was widespread and not only confined to the 16 complaints she had received, the Ombudsman recommended that a retrospective review should be carried out to trace and compensate all those who had been affected, and that further guidance should be issued making it much clearer who was eligible for funding.¹⁰ The Department of Health subsequently required Strategic Health Authorities to establish a single set of eligibility criteria for continuing care to be used by their respective Primary Care Trusts (PCTs) and NHS Trusts, to make arrangements to investigate cases where people may have been wrongly denied NHS continuing care, and to make appropriate restitution where this was found to be the case.

Recent developments

12. Although the review process has been beset with delays, over 12,000 cases were reviewed, and in 20% of cases financial repayment has been made. The Department of Health estimates that some £180 million will be spent on repayment in total.¹¹

13. The administrative cost of the confusion, inconsistency and opacity surrounding the system for funding NHS continuing care has been very high. It is easy to forget that behind each case reopened is an individual or a family who may have been wrongly denied continuing care funding, and that the human costs of the ongoing lack of clarity in this area have been even higher. As the Ombudsman described:

The people who have complained to me are not only concerned about what they see as the unfairness of the system for funding care, but about substantial financial injustice when it was applied to them. This arises because, if the NHS fully funds

⁹ The Health Service Ombudsman for England, *NHS Funding for Long Term Care*, HC 399, February 2003

¹⁰ The Health Service Ombudsman for England, *NHS Funding for Long Term Care*, HC 399, February 2003

¹¹ HC Deb, 16 September 2004, cols 175-176WS

continuing care in a care home, the patient does not have to make any contribution to the cost of that care. If not, the patient funds much of the care him or herself; or it is funded by local authority social services departments, with patients being expected to contribute according to their means. That can mean some patients having to use virtually all their accumulated life savings and capital from the sale of their home, to pay for care: whereas other patients who are judged eligible for full NHS funding for care in a care home make no financial contribution at all, regardless of their means. It is not surprising therefore that the decisions made by NHS organisations about eligibility for NHS funding arouse strong feelings.¹²

14. In December 2004, the Ombudsman published a further report, expressing concerns about the retrospective review process.¹³ At the same time, an independent review of the retrospective review process commissioned by the Department of Health raised similar concerns.¹⁴ On 9 December 2004, Dr Stephen Ladyman, the Parliamentary Under-Secretary of State for Community Care, announced the commissioning of “a national consistent approach to assessment for fully funded national health service continuing care”.¹⁵ We decided to undertake a brief inquiry into this area, and announced our inquiry on 21st January 2005, with the following terms of reference:

The Health Committee will undertake an inquiry into NHS continuing care. The inquiry will have the following terms of reference: to consider whether the announcement of the development of a national framework for NHS continuing care will resolve the long-standing problems of inconsistency and inequity, and make the Government’s policy more intelligible and fairer.

The Committee will examine:

The written Ministerial Statement on NHS continuing care issued by Dr Stephen Ladyman on 9th December 2004.

How the changes will build on the work already undertaken by Strategic Health Authorities in reviewing criteria for NHS continuing care and developing policies.

Whether the review of past funding decisions has succeeded in addressing the needs of patients wrongly denied NHS funding for their long term care.

What further developments are required to support the implementation of a national framework.

15. We took oral evidence from Dr Stephen Ladyman MP, Minister of State for Community Care, and officials from the Department of Health; from the Association of Directors of Social Services, Hounslow Primary Care Trust, Oxfordshire Learning Disability NHS Trust, County Durham and Tees Valley Strategic Health Authority and North West London Strategic Health Authority; from Age Concern, Citizens’ Advice, the

¹² The Health Service Ombudsman for England, *NHS Funding for Long Term Care*, HC 399, February 2003, para 2

¹³ The Health Service Ombudsman for England, *NHS Funding for Long Term Care – Follow up report*, HC 144, December 2004

¹⁴ Department of Health (Henwood M), *Continuing Health Care: Review, revision and restitution*, December 2004.

¹⁵ HC Deb, 9 December 2004, col 108 WS

Alzheimer's Association, and Barbara Pointon, a carer; from the Royal College of Nursing, the English Community Care Association, the British Geriatrics Society, and from University Hospital Lewisham NHS Trust; and from Trish Longdon, the Deputy Ombudsman, and Colin Houghton, an official from the Ombudsman's office.

16. We also received almost forty written submissions from patient organisations, individuals, Royal Colleges and legal firms. These were well considered and highly informative, and we are very grateful to all those who submitted evidence.

17. Since we finished taking evidence, a further development in this area has been the publication of the Government's Green Paper on Adult Social Care.¹⁶ Unfortunately we have not had time to consider these proposals in detail. However, although we welcome the Green Paper's aim to increase independence, choice and control, we do not believe its proposals materially alter the conclusions we have come to in this report.

18. We are indebted to our special advisers Melanie Henwood, an independent health and social care analyst, and Chris Vellenoweth, an independent health policy adviser.

¹⁶ Department of Health, *Independence, Wellbeing and Choice*, Cm 6499, March 2005

2 NHS Continuing Care – key problems and issues

19. In its written evidence, Citizens Advice argued that “decision making around eligibility for continuing care continues to be one of the least satisfactory areas of NHS practice.” In its view this stems from the complexity of the policy itself, which has proved “difficult to understand and to administer.” The organisation went on to emphasize the human cost of poor judgement in this area:

[The complexity of the policy] has resulted in poor decision-making by health professionals and lack of information for patients, leaving many confused and frustrated. Yet these decisions, which can be very marginal, have huge financial implications for patients and their families, often running into hundreds of thousands of pounds.¹⁷

20. The development of “a national consistent approach to assessment for fully funded NHS care” was announced by the Government in December 2004.¹⁸ In its statement, the Government said that the Department would work with SHAs to build on all the work to date done in this area. However, the wealth of evidence we have received in the course of this inquiry from organisations representing patients, carers and health and social care professionals convinces us that in the course of this review, the Government must take account of the views of patients, carers and professionals as well as NHS bodies.

21. In its forthcoming review of the system of NHS continuing care funding, it is vital that the Government draws on the views and experiences not only of NHS bodies and local authorities, but also of patients, carers and professionals. We therefore recommend that the Government’s review of continuing care funding arrangements take the form of a full, formal public consultation, in line with Cabinet Office recommendations.

22. In examining the problems and issues surrounding NHS continuing care, we begin by considering the separation of health and social care systems, which necessitates a whole range of distinctions between personal, nursing and health care which are largely artificial and impossible to administer, and which, arguably, underpin all the current difficulties in funding continuing care. We give detailed consideration to problems both with the continuing care eligibility criteria themselves and with the processes in place for applying the criteria through local assessment. We then discuss the retrospective review process, before finally examining a number of wider systemic problems with both continuing care and RNCC funding, which are fundamental to the provision of high quality continuing health and nursing care.

¹⁷ CC15

¹⁸ HC Deb, 9 December 2004, col 108 WS

3 Separation of health and social care

23. The separation of health and social care has meant that both the funding and provision of continuing care is beset with complexities. Our predecessor Committee summed up the background to, and consequences of, this divide in its report into the *Relationship between Health and Social Services*, published in 1999:

If we were building a new service to provide long term care to vulnerable groups it would seem logical to have a single, integrated community care provider so that service users, their carers and families could move seamlessly between services they may require over time. However, in Great Britain, nursing, medical and health care is provided by the NHS and social care is provided separately by local authority social services departments (SSDs). This separation developed in 1974 when local authority public and community health functions were transferred to new Health Authorities. For various reasons—historical, professional, administrative and financial—barriers have arisen between these services. These barriers frustrate the goal of "seamless" service provision and the division often appears confusing to the users of the services.

An effective relationship between health and social services is important for a variety of reasons. Since the implementation of the 1990 NHS and Community Care Act, and the subsequent transfer of elderly long-stay patients from NHS hospitals to residential care or their own homes, the number of people affected by co-ordination problems at the interface between health and social care services has increased.¹⁹

24. In nearly every inquiry undertaken in recent years, the absence of a unified health and social care structure has been identified as a serious stumbling block to the effective provision of care.²⁰ The problems relate to structure, financial accountability and, fundamentally, to the distinction between health care, which is mainly free at the point of delivery, and social care, which is means-tested and charged to the individual. The evidence we have received in this inquiry once again indicates that the artificial distinction between health and social care lies at the heart of most of the difficulties that have arisen concerning eligibility for continuing care funding.

25. It is clear that over the last twenty to thirty years, the gradual reduction in the number of long-stay hospital beds has meant that people who would previously have been looked after without charge in a hospital are now instead being cared for in fee paying nursing or residential homes, or in the community. The Minister did not dispute this:

Chairman: Would you accept that if a person may not necessarily need care by a registered nurse – would you accept that 25 years ago a person with those needs would probably be in hospital getting care?

Dr Ladyman: Yes.²¹

¹⁹ Health Committee, First Report of Session 1998 – 1999, *The Relationship between Health and Social Services*, HC 74 - I

²⁰ As above; see also, for example, Health Committee, Third Report of Session 2001-02, *Delayed Discharges*, HC 617 - I

²¹ Q318

26. As our evidence pointed out, this shift is in many respects a positive one as long stay wards were often dismal places, and care can often be delivered far more appropriately and effectively in a non-hospital setting, enabling people to maintain independence and in certain circumstances remain in their own homes.

27. However, what this has meant is that care that was previously provided in the NHS by doctors, nurses and others, and paid for from NHS funds, is increasingly being provided outside the NHS, whether in a nursing or residential home, or in people's own homes. The means of paying for this care, which was once simply automatically funded by the NHS free at the point of delivery, as any other NHS care would be, has now become infinitely more complex. If a patient is eligible for NHS continuing care, the entire costs will be met by the NHS. However if a patient is not deemed eligible for NHS continuing care but requires long-term residential care, the 'hotel' costs, for board and lodging, and 'personal care' costs, will be funded either by local authorities or by the resident themselves, or by a combination of the two. Nursing care needs will be paid for separately by the NHS, according to the fixed, three-banded tariff of the Registered Nursing Care Contribution (RNCC).²²

28. The confusion now arising from these complex and in some senses artificial definitions of different aspects of care is self-evident. Trish Longdon, the Deputy Ombudsman, told us:

The complainants who come to us come to us very confused about the whole issue: confused about what health care is; confused about the terms that are used; and confused about the distinctions that many people as providers make but which of course are meaningless to the users of those services. We have a very large amount of evidence to demonstrate that there is a real issue.²³

29. Barbara Pointon, a carer looking after her husband who has Alzheimer's Disease, gave a compelling description of how largely irrelevant these definitions of different types of care are for those actually receiving the care:

As a carer, as a receiver of this process, I am strongly of the opinion that the assessments are designed more to discover who should be funding the care rather than the level of care that should be provided to this patient. You talked right at the beginning about the division between social, personal and nursing care; and if only that were abolished, then a lot of this palaver and professional time would be done away with. I have a vision of the future that care is care whether you are talking about someone who is unable to dress themselves or about palliative care.²⁴

30. In evidence to a previous Health Committee, Frank Dobson MP, the then Secretary of State for Health, was asked to give a definition of the division between health and social care, and responded that he could not.²⁵ Over six years on, representatives from SHAs and

²² These contributions may not meet the full costs of the nursing care provided to an individual as the bandings are derived from a national average, notionally updated by inflation, and are not related to the staffing requirements imposed by the regulator (CSCI)

²³ Q193

²⁴ Q108

²⁵ Health Committee, First Report of Session 1998 – 1999, *The Relationship between Health and Social Services*, HC 74 – II, Q661

PCTs and Local Authorities, all senior officials working at the interface of health and social care on a daily basis, were similarly unable to supply a definition:

Chairman: Are we any nearer establishing a division?

Ms Gilley: I think we are nearer but I do not think ... any of us could give you a categoric definition²⁶

31. Nor did the Minister provide us with a clear definition. Instead, he argued that:

In the end it comes down to how closely social care and health professionals are working together; how well they understand each other's needs and are discussing these issues and are making sure they understand where funding of particular types of care should come, and the structure does not much matter.²⁷

32. However, the Minister's assertion that "the structure does not much matter" was not borne out by the evidence we received in this inquiry. John Pye, a community nurse from Liverpool representing the Royal College of Nursing, told us that for all his experience in the field of continuing care he could not supply a definition of the distinction between health and social care, and argued that this distinction instead distracted from what Mrs Pointon had argued should be the central concern of caregivers: the care needs of the patient:

I have been in the Health Service 37 years and I am no closer to finding the answers to what is health and social care. That is a perversity we have in dealing with probably our most dependent population. These people require continuing care. Whether it is continuing healthcare or continuing social care is a bit of a red herring really ... You suggested we move the demarcation line between health and social care, and I think we need to do that. We need to look at people holistically and see what their needs and care needs are.²⁸

33. As well as a move away from delivering ongoing care in NHS long-stay hospitals, the past two decades have seen a dramatic move away from traditional medical models of providing care. Tasks which were once the preserve of doctors and nurses are being competently carried out by others, including relatives and carers. Mr Pye gave several helpful illustrations:

As a couple of previous speakers clearly said, they provide quite a high level of nursing care to their loved ones and their families and friends. [In some circumstances] the vast majority of their care is provided by the mother and father. They carry out tracheotomy changes; they carry out ventilatory procedures on their own children.²⁹

34. Nursing tasks are also increasingly being delegated to care assistants, and some nurses are beginning to take on traditionally medical tasks, including prescribing. However, while

²⁶ Q2

²⁷ Q266

²⁸ Q133

²⁹ Q135

these more flexible ways of working are clearly beneficial both to professionals and to patients, they have brought an attendant set of difficulties, as definitions of types of care tend to be based on who is delivering the care. Mr Pye explained the problem:

It does not stop becoming a nursing task simply because the carers do it, but they do so under the guidance, supervision and training of the qualified nurses. It does not stop becoming a nursing task. The 2001 definitions of nursing care included those tasks delegated and supervised by nurses; however, when it comes to the funding issues around that care it ceases to be. The continuing health care and the RNCC clearly specify it is the work carried out by registered nurses. If you are not a registered nurse, you cannot carry out nursing care.³⁰

35. Mrs Pointon described how, in practice, defining care by who gives it can result in people wrongly being denied funding:

Malcolm was assessed three times for continuing care, and one of the criteria that was being used was that it was not nursing care because I was not a nurse, so the care was being defined by who gives it, which is fine in an institutional setting but does not work if you are working at home because you do not have a nurse on tap.³¹

36. Mrs Pointon successfully took her case to the Ombudsman, who ruled in her favour, agreeing that she was providing a level of care at least equivalent to that which her husband would have received as an inpatient, and Mrs Pointon was subsequently awarded continuing care funding for her husband.

37. Cath Attlee of Hounslow PCT also agreed that in today's changed healthcare landscape, it is not helpful to establish rigid divisions between health and social care:

As policy and practice change, the boundaries are shifted, so we are looking more and more at different professionals taking on different skills and mixing those. It is not helpful to define things specifically as a health input or a social care input.

38. The Ombudsman told us that in her view, professional joint working between health and social services which is now occurring in many areas, has largely left health and social care demarcation lines behind, as those working at the interface between health and social care strive to find innovative solutions to the problems caused by the distinction between health and social care. As Mr Pye described:

I was a community nurse in Liverpool way back in the 80s and 90s where we did merge the carers, the health and social care staff, because we had those disputes about who gives eye drops, who washes hair and their feet, and all those issues. We created a generic worker at that time, and they are spread round the National Health Service, the social services now anyway, particularly around the elderly. The only way forward is to come together and provide a generic workforce for the elderly with the specialist people involved in their care as well. Continuing health care gives an opportunity now towards the creation of that.³²

³⁰ Q135

³¹ Q94

³² Q134

39. Similar developments are occurring in mental health, where mental health professionals are increasingly working across the rigid demarcations of health and social care.

40. In recent years, in inquiries addressing as diverse a range of issues as the health needs of children and young people, inappropriate use of NHS acute beds, elder abuse and care for the terminally ill, this Committee and previous Health Committees have time and again been confronted by the problems caused by the current division of systems for funding and providing health and social care. Nowhere are these problems more evident than in the area of funding for continuing care, an area in which confusion has reigned for over ten years, resulting in frustration for health and social care professionals, and suboptimal care and financial hardship for some of our most vulnerable populations.

41. In practice the boundary between the two services has shifted over time, so that the long term care responsibilities of the NHS have reduced substantially, and people who in the past would have been cared for in NHS long stay wards are now often accommodated in nursing homes. This means that responsibility for funding long term care has to a major extent been shunted from the NHS to local authorities and individual patients and their families.

42. The question of what is health and what is social care is one to which we can find no satisfactory answer, and which our witnesses were similarly unable to explain in meaningful terms. The policy division between health and social care lags far behind practice in a number of areas, where, born of necessity, health and social care professionals have commendably developed innovative joint working practices. We welcome these developments and the use of pooled budgets and other flexibilities, which are beginning to break down the division between health and social care.

43. Debates about where the boundary between health and social care should be drawn have been complicated by further debates around the definitions of 'personal care' and 'nursing care', and have led to the absurd position where carers providing complex medical support for their loved ones are denied fully funded continuing care at home because they are not registered nurses. If the same care were to be given by a registered nurse, it would be regarded as nursing care and fully funded. Barbara Pointon, caring for her husband who has Alzheimer's, argued that in her experience the struggle to establish who should fund care has eclipsed the crucial issue of the patient's actual needs. She also emphasised that from a patient and carer perspective, 'care is care is care, whether you are talking about someone who is unable to dress themselves or about palliative care'.

44. We are convinced that so long as there are two systems operating according to quite different principles, the highly controversial issue of which patients qualify for fully funded NHS care, and which have to contribute some or all of the costs of care, will remain. We strongly recommend that the Government remove once and for all the wholly artificial distinction between a universal and free health care service operating alongside a means-tested and charged for system of social care.

45. Removing the boundary between health and social care would clearly have financial implications, as NHS services are currently free at the point of delivery, whereas social care is means-tested, with most people having to contribute towards the costs of their own personal or social care. According to Help the Aged, this would resolve many of the problems around continuing care:

If the Government committed to providing free care on the basis of need, then some of the difficulties relating to continuing care could be significantly alleviated as the debate about which agency is responsible for different aspects of care receded.³³

46. As we have noted previously, the Royal Commission on Long Term Care for the Elderly, set up by the Government to address the specific question of funding, concluded in 1999 that all personal care, including nursing care, should be free. The Government did not accept the Royal Commission's recommendation, and in evidence to us the Minister explicitly ruled out the possibility of re-opening discussions around this, arguing that cost pressures and demographic change would make a system of free personal care "unsustainable":

Will we go down the route of free personal care, which would be a way of resolving this point at a stroke? No, absolutely we will not. It would cost £1.5 billion at today's prices ... We know roughly speaking that there will be four times as many people needing care by 2050 ... by 2050 at today's prices the cost of free personal care will rise to somewhere between £8.5 billion and £10 billion. That will be close to 1 per cent of gross domestic product. There is just no way that that is a sustainable system.³⁴

47. The Minister emphasised the important distinction between free personal care and free long term care, pointing out that in Scotland, where all personal care is free, if a person goes into residential care, they still have to pay for their board and lodging, and are not entitled to collect attendance allowance. In the Minister's view, many of those currently campaigning for free personal care are doing so under the misapprehension that free personal care and free long term care are synonymous.³⁵ The Minister also argued that a system of free personal care could have significant disadvantages over the existing system. Firstly, in 2001 the Government introduced a policy to prevent people from having to sell their homes to fund residential care. Under this scheme, councils can put a charge on people's homes to be sold after their death. The Minister stated that in his view, this scheme would have to be abolished to cover the costs of introducing free personal care.³⁶ Secondly, the Minister argued that in Scotland, where personal care is free, someone being cared for in their own home may be forced to move to a residential care home if it became cheaper to care for them in an institutional setting than to care for them in their own home, despite the fact that most elderly people prefer to be cared for in their own homes.³⁷

³³ CC28

³⁴ Q321

³⁵ Q317

³⁶ Q317

³⁷ Q317

48. This inquiry has focussed in the main on securing improvements to continuing care under the current system, and for this reason we have not sought detailed evidence on the most up-to-date estimates of costs of free personal care. However, using the Minister's own figures, the £1.5 billion he estimates it would cost to provide free personal care today is dwarfed by the current £60 billion spend on health care³⁸; equally, in his report *Securing our Future Health*, Sir Derek Wanless estimated that even by 2023 at least £154 billion per year is likely to be spent on the NHS, and over 10% of GDP on health care.³⁹ It is also worth noting that after a year long inquiry into this subject, the Royal Commission on Long Term Care for the Elderly concluded that the UK was not facing a “demographic timebomb”, and that as a result of this the costs of providing free personal care would be affordable.⁴⁰

49. Managing and defending the boundary between health and social care carries significant administrative costs, and the costs of free personal care, if introduced, would have to be offset against the cost savings that would be generated from eliminating these administrative costs. The disputes over delayed discharges from the NHS into social care, which have had to be addressed through legislation, are just one example of this. When we put this point to our witnesses, they agreed. Elaine McHale of the Association of Directors of Social Services told us that in her view,

There is lot of public funding being spent on legal definitions, particularly around this policy guidance, and much wasted time and energy in trying to achieve an outcome for individuals in different local authorities.⁴¹

50. Although the Minister told us the Government had no estimate for how much this might be, he concurred with the view that there were costs: “I agree with you that there must be a cost to it”, but said he thought the cost would not be substantial.⁴²

51. We are aware that the Kings Fund has commissioned Sir Derek Wanless to undertake a review of the challenges and demands facing social care, and the resources that will be needed to deliver social care fit for the 21st century.⁴³

52. During this inquiry, we have heard renewed calls for personal care to be provided free of charge, which would be a way, to use the Minister's phrase, of resolving many of the difficulties arising from the boundary between health and social care “at a stroke”. However, the Minister stated categorically that the Government will not reconsider this option, arguing that it would be financially “unsustainable”. While we have not focussed in depth on this issue during this inquiry, we dispute the Minister's argument that funding personal care would be financially “unsustainable”. It is clearly for Governments to decide their own spending priorities – however, we maintain that with political will, the resources could be found to fund free personal care. Moreover, the costs of providing free personal care need to be offset against the current

³⁸ Department of Health, Departmental Report 2004, Cm 6204, April 2004, Figure 3.1

³⁹ Derek Wanless, *Securing Our Future Health – Taking a Long Term View*, April 2002, Summary

⁴⁰ Royal Commission on Long Term Care, *With Respect to Old Age: Long Term Care – Rights and Responsibilities*, Cm 4191 – I, March 1999, Executive Summary and Summary of Recommendations

⁴¹ Q3

⁴² Q267

⁴³ <http://www.kingsfund.org.uk/news/news.cfm?contentID=276>

administrative costs associated with policing the divide between health and social care. We recommend that debate in this area is informed by the outcome of the Kings Fund study into future social care resource requirements which is currently being undertaken by Sir Derek Wanless.

53. We recognise that a unification of all health and social care responsibilities would require primary legislation which is not an early prospect, and we have therefore framed our subsequent recommendations about continuing care in the context of today's statutory provisions. However, we urge the Government to accept our central conclusion that removing the structural barriers between health and social care is the only way to satisfactorily address these, and a great many other problems, in the long term.

4 The need for a single set of national eligibility criteria

54. The criteria for determining eligibility for NHS continuing care, which were issued in 1995, are broad and vague, and include one or more of the following:

Where the complexity or intensity of their medical, nursing care or other clinical care or the need for frequent not easily predictable interventions requires the regular (in the majority of cases this might be weekly or more frequent) supervision of a consultant, specialist nurse or other NHS member of the multidisciplinary team;

Who require routinely the use of specialist health care equipment or treatments which require the supervision of specialist NHS staff;

Who have a rapidly degenerating or unstable condition which means that they will require specialist medical or nursing supervision.

In addition patients who have finished acute treatment or inpatient palliative care in a hospital or hospice, but whose prognosis is that they are likely to die in the very near future should be able to choose to remain in NHS funded accommodation, or where practicable and after an appropriate and sensitive assessment of their needs, to return home with appropriate support.⁴⁴

55. Health Authorities were required to develop their own, more detailed operational policies and eligibility criteria, based on this broad framework. While this approach had the advantage of allowing Health Authorities flexibility of interpretation to meet the specific needs of their local populations, it also meant that eligibility criteria could vary substantially from area to area, a point made by a predecessor Health Committee in 1995:

We share the concerns of those of our witnesses who argued that local eligibility criteria might create unacceptably wide variations in the provisions of NHS services ... on the grounds of equity, we believe that the nationally set framework should include the eligibility criteria for long term care to define what the NHS, as a *national* service, will always provide⁴⁵

56. Successive Governments did issue guidance to Health Authorities on continuing care criteria in order to promote some degree of coherence across the NHS. The 1995 guidance was followed by further guidance in 1999 and again in 2001.⁴⁶ However, this was clearly not sufficient to ensure correct and consistent interpretation of continuing care eligibility criteria as, in February 2003, the Ombudsman published a highly critical report emphasising the fact that criteria for continuing care had clearly been interpreted and

⁴⁴ Department of Health, *NHS Responsibilities for meeting continuing health care needs*, HSG(95)8, 1995

⁴⁵ Health Committee, First Report of Session 1995-1996, *Long Term Care – NHS Responsibilities for Meeting Continuing Health Care Needs*, HC 19-I, paras 50-51

⁴⁶ Department of Health, HSC 1999/180 *Ex-parte Coughlan: follow up action continuing health care follow up to the Court of Appeal judgement in the case of R V North and East Devon Health Authority 1999*; Department of Health, HSC 2001/015 LAC(2001)18, *Continuing Care: NHS and Local Councils' responsibilities*, 2001

applied differently by different Health Authorities, leading to inequities in access to funding for continuing care. The Ombudsman concluded that:

There is evidence that the Department of Health's guidance has been misinterpreted and misapplied by some Health Authorities and Trusts, leading to hardship and injustice for some individuals. But there are also more fundamental problems with the system. The Department of Health's guidance and support has not provided the secure foundation needed to enable a fair and transparent system of eligibility for funding to be operated across the country.⁴⁷

57. The Ombudsman made three key recommendations:

PCTs and Strategic Health Authorities (SHAs) should trace those people who might be affected, review their circumstances and where justified make restitution, and that the Department of Health should guide and support them in that work.

SHAs should review the criteria used in their areas since 1996 (when written criteria were first required) for compliance with the law as it stands and with national guidance, and that

The Department of Health should review its own guidance, making it much clearer who was eligible for funding

58. Responding to the Ombudsman's report, the Government accepted the need for retrospective reviews. However, rather than the Department of Health itself reviewing guidance and criteria, as the Ombudsman had recommended, the Department instead issued instructions that the 28 new SHAs, which had recently superseded the 95 previous Health Authorities, should each develop one set of criteria, effectively assimilating 95 sets of criteria into 28.

59. While reducing 95 sets of criteria into 28 is clearly a step towards greater consistency, according to our witnesses there is still considerable scope for local variation. Many submissions referred to the "post-code lottery" evident from a comparison of SHA policies and guidance. Anne Williams of Citizens' Advice, for example, told us that "continuing care is the biggest postcode lottery of them all. You will be aware on this Committee of the problems with cancer care and all the rest of it, but it is nothing to continuing care – it is so different."⁴⁸

60. We took evidence from two SHAs, and we asked them whether they took account of the criteria of neighbouring SHAs when preparing their own, in order to ensure consistency. We were told by Michael Young of North West London SHA that other SHAs had looked at their criteria to see "what was good and what was relevant to them", and Denise Gilley of County Durham and Tees Valley SHA told us that they had had "detailed discussions" with one neighbouring SHA, and "some discussions" with others.⁴⁹ While it is commendable that SHAs are working together to share good practice, this sort of

⁴⁷ Health Service Ombudsman for England, Press notice 18 February 2003, OMBUDSMAN UPHOLDS COMPLAINTS ABOUT REFUSAL OF NHS FUNDING FOR LONG TERM CARE

⁴⁸ Q100; see also CC01

⁴⁹ Qq31-33

informal joint working is clearly not sufficient to ensure consistent criteria across the country.

61. The Minister accepted that reducing 95 different sets of criteria to 28 would not have eliminated all inconsistency, but argued that these 28 criteria were, in fact, more consistent than their predecessors:

You are right that on the face of it we only reduced it from 95 to 28, and therefore there were 28 different postcode lotteries; but actually those 28 were based on the national guidelines, so there should have been far more consistency between those 28 than ever there was between the 95 they replaced.⁵⁰

62. However, Mr Young's evidence illustrated that some real problems have persisted as a result of SHAs having different criteria:

If people move out of area, and particularly in terms of wanting annual reviews (and it is very hard in London to do the annual reviews as we do send a lot of people out of area) someone who understands our criteria and our assessment tools would need to be able to assess them.⁵¹

63. According to Elaine McHale of the ADSS, the introduction of Payment by Results is going to compound these problems, as staff will be expected to use different interpretations of continuing care criteria to assess patients coming in from a far wider range of different locations than is currently the case.⁵²

64. There is also evidence of considerable variation within SHAs, with PCTs, NHS Trusts and Local Authorities (Las) applying criteria differently. The issue of implementing criteria is discussed in detail further on in our report.

65. The Minister agreed that consistency in determining eligibility for continuing care funding was of crucial importance, and told us his ultimate aim:

Broadly speaking, we want to end up with a system where absolutely everybody in England will be able to say, "the assessment I have had would have come to exactly the same conclusion, whether it was held in London or Carlisle or wherever it was."⁵³

66. To address the problem of different criteria in different SHA areas, the evidence received by the Committee has almost universally been in favour of the introduction of a single, national set of eligibility criteria. This was also reflected in the report of the independent review commissioned by the Department of Health. Although the Ministerial Statement issued in December 2004 only referred to a national 'framework', the Department's memorandum suggested that national criteria were being planned.⁵⁴ However, the Minister was unable to give us a categorical assurance that this would be the case:

⁵⁰ Q271

⁵¹ Q36

⁵² Qq 7-8

⁵³ Q272

⁵⁴ CC09, para 5

John Austin: The new national framework will have a single set of national eligibility criteria?

Dr Ladyman: We have those discussions, but my belief is that that is where we will end up. This is a consultation; we are bringing the 28 strategic health authorities together to identify best practice. They are giving us a very clear message. They want to have one single set of national eligibility criteria, so my belief is that is what we are very likely to agree with. If, in the course of these discussions, we find that is not practical, we will have to have something different.⁵⁵

67. The NHS has an urgent need for a single, universal set of national eligibility criteria for continuing care to end the inequities and inconsistencies that have developed as a result of the current system. It is unacceptable that in one part of the country a person with a specific set of care needs would be assessed as qualifying for fully funded NHS continuing care, while a person with identical needs living in a different part of the county would be deemed ineligible, and would potentially have to fund all or part of their care from their own means. We welcome the Minister's aim of addressing this problem, and we welcome his conviction that the current review will result in the development of a single set of national eligibility criteria. However, he was not able to give us a categorical assurance on this point. A single, national set of eligibility criteria for NHS continuing care is crucial to ensure coherence and equity, and we urge the Government to ensure that a single set of national eligibility criteria is developed.

68. Much of the evidence we have received indicated that the introduction of a single set of national criteria is long overdue. Indeed, this issue was first raised by a predecessor Health Committee as long ago as 1995, but successive Governments appear not to have recognised this problem until the Ombudsman published her report in 2003. It is regrettable that the Department's own internal systems did not identify this problem sooner, and that it took 16 complaints to the Ombudsman before it was finally addressed.

69. Perhaps even more worryingly, the Ombudsman recommended that the Department should provide further national guidance to clarify the situation in February 2003, but it was not until almost two years later, in December 2004, that the Department acted on this by announcing the development of a new national framework and guidance for continuing care. The lack of further guidance, according to the Ombudsman, had a direct bearing on the retrospective review process:

Between the period of the first report and the second report, the February 2003 and the December 2004 reports, not only did we have the complaints coming through, we had a great number of practitioners from trusts and Strategic Health Authorities telephoning us almost on a weekly basis to say, "We are struggling with this criteria. We are trying to do our best. Can you come down and train us? Can you tell us what to do? Or, better still, can you come and sit on the panel and do this with us?" Of course, we had to keep our distance from that. I think there were considerable efforts to try to get this right, but they did not have the guidance or leadership at that time to get it right.⁵⁶

⁵⁵ Q273

⁵⁶ Q245

70. Ms McHale also argued that the Department should have been more proactive in supporting SHAs:

I think more could have been done with regard to clarification and transparency about the definitions and the applications.⁵⁷

71. The Minister told us that national criteria and guidance were not prepared after the February 2003 report for logistical reasons:

We did that because, frankly, going from 95 to one, at a time when we had this huge review to carry out, our judgment was that it would just have been an impossible task to do that.⁵⁸

However, while we accept that carrying out the retrospective reviews entailed a significant increase in workload for SHAs, this does not explain why the Department itself was unable to start work on developing a single set of criteria.

72. We are concerned that it has taken so long for the Department to recognise and address the problem of inconsistent continuing care criteria. We recommend that the Department should consider its own internal monitoring processes with a view to detecting problems like this at an earlier stage in future. It also seems that an opportunity was missed, at the time of the Ombudsman's report in February 2003, for the Department to start work on developing an urgently needed single set of national criteria. The Department ought to have acted sooner to develop a single set of national criteria, and we recommend that this work be completed as a priority, within the 12 month timescale indicated by the Minister.

⁵⁷ Q15

⁵⁸ Q271

5 Problems with the existing continuing care eligibility criteria

73. The development of a single, national set of continuing care criteria presents an opportunity not only to achieve consistency across England, but also to redesign the criteria to address enduring problems with existing criteria. Our evidence has identified several major concerns:

- that current criteria take insufficient account of mental health needs, particularly disadvantaging those with dementia;
- that criteria must take account of a wide range of needs, not only those of older people;
- that the lack of clarity about the distinction between continuing care criteria and the criteria for assessing the RNCC must be resolved;
- and, finally, that existing criteria may not in fact be compatible with the Coughlan judgement.

Insufficient focus on mental health needs and dementia

74. Much of the evidence we have received highlights particular difficulties around the area of mental health, and specifically dementia, which it is estimated affects as many as 75% of residents in care homes.⁵⁹

75. The Department of Health has stated repeatedly that eligibility for continuing care is not based on diagnosis but on need, and the Minister explained this in detail to us:

People with dementia are as entitled to NHS continuing care as anybody else. However, the judgment has to be whether they need, in order to maintain their condition or to improve their condition, the regular involvement of healthcare professionals. If somebody with dementia does not need that regular involvement of healthcare professionals, then they will fall outside the criteria for NHS continuing care. If they do require the involvement of healthcare professionals, they will come inside the criteria and they will get their NHS continuing care, as was the case with Mrs Pointon. She did get for her husband NHS continuing care.⁶⁰

76. The Pointon case is a helpful example, but not, as the Minister implied, of the continuing care criteria working effectively to take account of the needs of those with dementia, but rather of the reverse. Barbara Pointon only succeeded in securing continuing care funding for her husband, who suffers from Alzheimer's, after a lengthy battle which culminated in her taking her case to the Ombudsman.

77. Mrs Pointon described her experiences to us:

⁵⁹ Q112

⁶⁰ Q315

What has got to me is the notion that one size fits all. Malcolm's assessments took very little account of important features of dementia such as panic attacks, hallucinations, inability to communicate or understand, and the psychological effects of the illness. Unless you ask the right questions, you will not get the right answers in the assessments.⁶¹

78. Upholding Mrs Pointon's complaint, the Ombudsman concluded:

The local eligibility criteria reflected the guidance from the Department of Health, but ... the ambiguities within the criteria, particularly those referring to dementia and sensory and/or physical disabilities, caused staff to produce inappropriate assessments that concentrated solely on Mr Pointon's physical needs.⁶²

79. The current criteria for continuing care focus on the issue of stability. However, according to the Alzheimer's Society, people in the late stages of dementia are often classed as stable and predictable and, as their condition worsens, they in fact become less likely to qualify for NHS continuing care:

The ... criteria that we are really concerned about is the one around "stable and predictable". It is probably the one that we get most feedback on, and anger from carers. If you have Alzheimer's you are going to get worse and you are going to decline, and ultimately you are going to be in the palliative stage of dementia. Our experience and feedback from people is that as you decline you are less likely to be eligible for continuing care, which is not what you expect. If you are sitting very passively or lying in a bed, you are perceived to be easier to care for. We do not agree with that; we think you need much more intensive support to help you have a good quality of life.⁶³

80. Julia Cream of the Alzheimer's Society argued that, as most nurses have very little training in dementia, they often unable to recognise mental health needs in that group when carrying out assessments.⁶⁴ This view was endorsed by Mr Houghton of the Ombudsman's office:

In some cases it became obvious from looking at the nursing notes or the care home notes, that there were, for example, regularly occurring psychological needs. With the best will in the world, a single nurse looking alone at these may not be able to pick these up or may not see the significance of them when seen in a pattern of behaviour.⁶⁵

81. It is not solely those with Alzheimer's who appear to be suffering under these criteria. According to the Motor Neurone Disease Association, existing Department of Health guidance on continuing care clearly indicates that Motor Neurone Disease (MND) is "exactly the type of complex, degenerative condition that the scheme is designed for, yet

⁶¹ Q108

⁶² Health Service Ombudsman for England, *The Pointon Case*, November 2003, para 43
<http://www.ombudsman.org.uk/pdfs/pointon.pdf>

⁶³ Q113

⁶⁴ Q115

⁶⁵ Q207

currently, many people with MND are unable to obtain the continuing care to which they are entitled due to geographical variations in the interpretation and application of the eligibility rules.” They went on to give stark examples of this:

We know of one lady who died just after being refused continuing care on the grounds that she didn't have pressure sores or need daily visits from her GP. This was actually because of the quality of the care she was receiving in a very good nursing home.

There is also evidence to suggest that those people handling continuing care applications do not have a good enough understanding of the conditions they are likely to encounter. We are aware of cases where a request for an assessment has been questioned because the person “only has MND”.⁶⁶

82. The Parkinson's Disease Society raised similar concerns:

Too often we receive calls and letters outlining situations where through a lack of understanding about the impact of the disease people have been denied NHS funding for their long term care ... The fundamental problem with the NHS continuing framework as it currently stands is that in most cases people in later stages of progressive neurological conditions are not recognised as entitled to full NHS continuing care ... The inequality experienced by people with Parkinson's disease is apparent when compared to someone with a “recognised” illness.⁶⁷

83. These concerns were supported by Mackintosh Duncan, a firm of solicitors who were involved in the Coughlan case, and specialise in the law around continuing care:

We have been assisting many people with mental health difficulties and/or learning disabilities in relation to continuing care issues. Our experience is that it is most difficult, if not impossible, to obtain fully funded NHS care for a person with mental health difficulties or learning disabilities unless they have the most extreme challenging behaviour, or their mental disabilities are accompanied by physical health needs.

There seems to be an assumption that mental health nursing or learning disabilities nursing is ‘non medical’ due to the fact that it involves high levels of supervision, as opposed to physical invasive treatments.⁶⁸

84. Our evidence indicates that current eligibility criteria for NHS continuing care are heavily weighted towards physical needs, to the detriment of mental health and psychological needs. It strikes us as perverse that, under current criteria, in the case of Alzheimer's Disease the further a person's illness progresses, the less likely they are to qualify for continuing care funding, even though they in fact need more intensive health care to maintain a good quality of life. Sufferers from other progressive and degenerative conditions, including Motor Neurone Disease and Parkinson's Disease, are similarly disadvantaged. We recommend that the Government's new national

⁶⁶ CC22, paras 3.4.1-2

⁶⁷ CC24, paras 3.1, 6.1

⁶⁸ CC32

eligibility criteria be designed explicitly to give the same weight to mental health and psychological needs as to physical needs.

Flexibility to meet a wide range of needs

85. Although the majority of those receiving NHS continuing care funding are elderly people, the issue is not confined to older people, and indeed there are several other groups who make significant use of continuing care funding, including children, adults with learning disabilities and mental health needs, people with chronic, degenerative conditions, and people who are terminally ill.

86. We heard differing views about whether or not separate criteria should be established to cater for the differing needs of different client groups. Yvonne Cox, Chief Executive of Oxfordshire Learning Disability NHS Trust, argued that the criteria did need to be different to take account of different needs and expectations at different stages of life, and that current guidance took insufficient account of other needs: “the guidance is predominantly around older people, delayed transfers and so on, and the issues those raise.”⁶⁹

87. However, Cath Attlee of Hounslow PCT argued that the same principles of promoting and enabling independence should be applied to older people as well as to younger adults. Elaine McHale of the ADSS suggested that the inclusion of children within the same framework as younger adults and older people could have a positively beneficial effect:

I firmly believe that if children were accommodated within the continuing care policy, then you would see a different long term commissioning arrangement of service provision, which would build for the future and contribute to the aspirations we have around government policy.⁷⁰

88. It is not appropriate to produce separate eligibility criteria to cover different client groups. However, eligibility criteria must be able to adequately meet the needs of all those who need continuing care, whatever their age or diagnosis, and the Government should take account of this in developing its new national eligibility criteria for NHS continuing care.

Confusion over the Registered Nursing Care Contribution

89. The Registered Nursing Care Contribution (RNCC) system was introduced in October 2001 on a phased basis, to transfer responsibility for funding the nursing care⁷¹ of those in care homes to the NHS. Under the RNCC system an assessment of a patient’s nursing needs is carried out by a qualified nurse, and a patient will be graded according to a three banded system, which will determine the level of funding they get for their nursing care needs:

- low (£40pw from 1 April 2005),

⁶⁹ Qq12-13

⁷⁰ Q14

⁷¹ Care provided by registered nurses

- medium (£80pw from 1 April 2005) and
- high (£129pw from April 2005).

90. The Department of Health has provided the following guidance for assessment for the RNCC:

The High Band - People with high needs for registered nursing care will have complex needs that require frequent mechanical, technical and/or therapeutic interventions. They will need frequent intervention and re-assessment by a registered nurse throughout a 24 hour period, and their physical/mental health state will be unstable and/or unpredictable.

The Medium Band - People whose needs for registered nursing care are judged to be in the medium banding may have multiple care needs. They will require the intervention of a registered nurse on at least a daily basis, and may need access to a nurse at any time. However, their condition (including physical, behavioural and psychosocial needs) is stable and predictable, and likely to remain so if treatment and care regimes continue.

The Low Band - The low band of need for nursing care will apply to people *who are self-funding* whose care needs can be met with minimal registered nurse input. Assessment will indicate that their needs could normally be met in another setting (such as at home, or in a care home that does not provide nursing care, with support from the district nurse), but they have chosen to place themselves in a nursing home.⁷²

RNCC payments are made directly to the nursing home where the patient is a resident, as under current legislation the NHS cannot reimburse individuals directly.

91. Although the RNCC system should technically operate separately from the continuing care system, with continuing care funding being provided to those with the very highest needs, and the RNCC system applying to those who do not qualify for continuing care funding but still require nursing care, the evidence we received suggested considerable confusion and significant overlap between the two systems. This is partly because the wording used in the RNCC criteria is almost identical to that used for continuing care. To qualify for high band nursing care, people will need to be assessed as having an “unstable” or “unpredictable” state of physical health. However, as people assessed as qualifying for fully funded continuing care must also have “unstable” and “not easily predictable” health care needs, this raises the question of whether it is possible to distinguish between high band nursing care and continuing care funding. This confusion was raised in many written submissions, and was also a major finding of the independent review.

92. John Pye of the Royal College of Nursing argued that the confusion stemmed from two policies developed in isolation without adequate reference to each other:

It came along as a reaction to the long term commission. It also did not take into account the policy we already had in place for continuing health care, and the two

⁷² <http://www.dh.gov.uk/assetRoot/04/07/10/16/04071016.pdf>

sides have never married up. I was listening to previous speakers about the combinations and the relationship between the RNCC and continuing healthcare. It was never thought about when RNCC came out, and we have ended up with two policies and two procedures matching in everything including the words, which places a great difficulty on us within the nursing sector and certainly within PCTs in trying to disseminate and make decisions on who funds and who does not.⁷³

93. This confusion was also noted by the Ombudsman in her report and, following legal advice, her office has written to the Department to seek clarification about whether, given the similarity of the wording used in both sets of criteria, those who have been found to qualify for high band free nursing must in fact also meet the criteria for full funding:

It seems to us, and is supported by our legal advice, that if a person's needs for registered nursing care are deemed to be at high band RNCC level, it is difficult not to say that that person should also be eligible for NHS continuing care funding, given the similarity of the wording ... it is difficult to see how a person with healthcare needs that properly place him or her at high band RNCC would even have reached the stage of an RNCC assessment, had he or she been properly assessed for NHS continuing care. This is because the level of health care needs that warrant high band RNCC would seem to be, at the least, equivalent to those that should qualify a person for continuing care funding, if not higher.⁷⁴

94. Responding to the Ombudsman's letter, the Department acknowledged that confusion had arisen at a local level. Although the Department's letter did not specifically address the Ombudsman's argument that if a person's needs for registered nursing care are deemed to be at high band RNCC level, that that person should probably also be eligible for NHS continuing care funding, given the similarity of the wording, the letter did suggest that this confusion will be resolved in the forthcoming review:

When the Minister, Stephen Ladyman, announced the work to develop a national framework for NHS continuing care he made it clear that this should include NHS funded nursing care. Also the development of the Single Assessment Process, and ensuring all aspects of care needs are taken into account through that process, has already been identified as the way to make sure the process is handled correctly and consistently. This will be the opportunity to clear up confusion and there could be options for a significant change to the interface between NHS funded continuing care and NHS funded nursing care.⁷⁵

95. In oral evidence, the Minister told us that there were no plans at the moment to integrate the two systems, although he did not rule out the possibility. However, he did offer to ensure that, if the two independent systems remain, detailed guidance will be issued to clarify the distinction between continuing care and high band RNCC.⁷⁶

⁷³ Q132

⁷⁴ CC23B

⁷⁵ CC09D

⁷⁶ Q328

96. It seems to us a nonsense that two separate systems exist for assessing eligibility for fully funded NHS continuing care and for nursing care contributions as fundamentally both systems are doing the same thing, which is determining NHS funding of ongoing health care. We have heard from several authoritative sources, including the Ombudsman, that the criteria for assessing eligibility for continuing care and high band nursing care are virtually indistinguishable from each other, causing considerable problems for those charged with applying them, and raising the possibility that, in fact, everyone who qualifies for high band RNCC should also automatically qualify for fully funded continuing care.

97. We are surprised that these two distinct policies regarding the funding of ongoing health care have been developed by the same Department with seemingly no regard for ensuring coherence or harmony between the two systems. We urge the Government to put right this confusion and end unnecessary bureaucracy immediately. It seems to us that the simplest way to achieve this would be to integrate the two systems. If the two systems continue to co-exist, there must be clarification of the interaction between them, and we recommend simplification of the banding system.

Questions over whether the criteria are actually Coughlan-compliant

98. The Law Society, Solicitors for the Elderly, and Mackintosh Duncan argued that current criteria, both for continuing care and for nursing care contributions, set the bar too high to be ‘Coughlan-compliant’.⁷⁷

99. In 1999, the judge in the Coughlan case ruled that, as Pamela Coughlan’s needs were primarily for health care, the Health Authority was liable to fund her entire care package – in other words, that she should qualify for fully funded NHS continuing care. Thus the judgment in *Coughlan* establishes that where a person’s primary need is for health care, and this is more than ‘ancillary’ or ‘incidental’ to their needs for accommodation, the NHS is responsible for the full cost of the package. Social services authorities may only purchase nursing care in strictly limited situations, in accordance with the judgment.

100. The Department of Health subsequently issued guidance to Health Authorities asking them to ensure their eligibility criteria were ‘Coughlan-compliant’. Mackintosh Duncan described the test of ‘Coughlan-compliance’ very simply:

Any national framework/criteria must operate so that if Ms Coughlan were to present herself in any area of the country, she would be eligible for fully funded NHS continuing care.⁷⁸

101. According to the Department of Health, all 28 sets of eligibility criteria now operating are legal and in line with current guidance.⁷⁹ However, Mackintosh Duncan, the Law Society and Solicitors for the Elderly all argued that the Coughlan case would itself have failed to meet the requirements of the guidance on eligibility criteria, as Pamela Coughlan’s

⁷⁷ CC35, CC17, CC32

⁷⁸ CC32

⁷⁹ HC Deb, 9 December 2004, col 108 WS

condition was stable and predictable, but with a high level nursing care needs.⁸⁰ They also argued that, as the guidance is currently written, Pamela Coughlan would not have been eligible for high band nursing care, or even, in all likelihood, for medium band nursing care:

Ms Coughlan’s condition and needs were said by the Court of Appeal to fall wholly within the funding responsibilities of the NHS. However, her particular needs are considerably less than the majority of residents in nursing homes. Therefore, applying the RNCC tool, Ms Coughlan would not meet the medium or high band of RNCC, let alone the (higher) threshold of fully funded NHS care. Given the comments of the Court of Appeal regarding her individual needs, we consider that this has been overlooked by health authorities in developing their criteria.⁸¹

102. Mackintosh Duncan went on to assert that, accordingly, very few of the criteria currently being used by SHAs were actually ‘Coughlan-compliant’:

We have seen many sets of eligibility criteria currently being operated. In our view, none of those criteria are in accordance with the Coughlan judgment. In many cases, people would be eligible only if they were near death. There continues to be a mistaken belief that chronic health care for patients in a stable condition is no longer the responsibility of the NHS. This was the very error which led to the Coughlan case being brought.⁸²

103. The Minister has stated that all 28 sets of eligibility criteria now operating are legal and in line with current guidance. However, we have received evidence which calls this in to question, arguing that in fact the Coughlan case itself would have failed to meet the requirements of current eligibility criteria, either for NHS continuing care, or for high or even medium band RNCC, as Pamela Coughlan’s condition was stable and predictable, although she had high level nursing care needs. Mackintosh Duncan solicitors, who specialise in continuing care law, told us that of the many sets of eligibility criteria they have seen which are currently being used, “none of those criteria are in accordance with the Coughlan judgment”. These are very serious charges which the Government must answer. The new national eligibility criteria must be explicitly Coughlan-compliant, ensuring that all people whose primary need is for health care will receive fully funded care, even if this requires a fundamental revision of the definitions and terminology of the criteria.

⁸⁰ CC35, CC17, CC32

⁸¹ CC32

⁸² CC32

6 Problems with current implementation of the eligibility criteria

104. Currently, local criteria are devised by SHAs, but they are implemented by a variety of groups. Assessments for continuing care are often carried out in an acute hospital trust, before a patient is discharged. They may also take place in a nursing home, care home, or in the patient's own home. Eligibility for continuing care is meant to be assessed by a multi-disciplinary team. Each PCT is then responsible for funding both continuing care and the RNCC. In some areas, a panel convened by the local PCT will consider all applications for continuing care funding after the multidisciplinary assessment, before making a final decision about whether or not funding will be granted.

105. According to much of our evidence, translating policy into practice and ensuring that the criteria are implemented fairly and consistently presents just as much of a challenge as getting the criteria themselves right. Our evidence reveals as much, if not more, concern about implementation of the criteria. These concerns centre around:

- The slow implementation of the Single Assessment Process
- Lack of access to assessments
- Inequities arising from different application of criteria
- Quality of assessment
- The crossover with assessment for RNCC
- PCT panels and funding decisions
- Monitoring of implementation and assessment

The Single Assessment Process

106. The Single Assessment Process (SAP) was announced in 2000, and was a core element of the *National Service Framework for Older People* published in March 2001. The intention of a single assessment process operating across health and social care for older people is that there should be a more standardised approach across areas and agencies so that older people's care needs are assessed thoroughly and accurately, but without procedures being needlessly duplicated by different agencies. The SAP began to be phased in in April 2002. Guidance advised agencies to develop systems based on four broad types of assessment:

- Contact assessment
- Overview assessment
- In-depth assessment, and
- Comprehensive old age assessment.

107. The outcome of the assessment process should be that a care plan is drawn up in consultation with the service user (and their carers if relevant), that sets out the objectives of providing help and the anticipated outcomes. The assessment for eligibility for continuing care is an integral part of the SAP, as is the determination of the RNCC for any individuals for whom it has been agreed that admission to a care home providing nursing care offers the best environment for meeting their care needs.

108. The Minister told us that the SAP should be the basis of all assessments for continuing care and RNCC, and that good progress was being made in implementing the SAP: “the single assessment process is being implemented very successfully around the country, and it is available everywhere.”⁸³ However, he then went on to suggest that implementation was in fact variable, as it was “working better in some places than others”.⁸⁴ He told us that any older person being discharged from an acute ward should have gone through the SAP and should have automatically been considered for NHS continuing care before discharge. But his evidence suggested that this was not happening universally, as he emphasised the need to “find a way [to] ensure that all older people undergo the single assessment process”.⁸⁵

109. Our evidence suggested that the SAP is not being implemented consistently, as Jo Peck of University Hospital Lewisham NHS Trust informed us:

Dr Taylor: Has the introduction of the single assessment process made any difference?

Ms Peck: No, because we are not using the single assessment process across the board yet. Actually, we have just had a case that went to panel this week in Lewisham that had the single assessment, and it was deferred because the assessment was not deemed appropriate; so they have now got to go back and re-assess under continuing care.⁸⁶

110. The Single Assessment Process (SAP) was intended to integrate assessment processes across health and social care, and to ensure that all older people were given a high-quality multi-disciplinary assessment of their needs. However, we are not convinced that implementation of the SAP system is progressing as swiftly and effectively as the Minister implied. We recommend that the Government takes steps to ensure that this is addressed.

Access to assessments

111. Very worryingly, we have received evidence that many patients are not being offered access to any sort of assessment at all. Citizens’ Advice told us:

A bureau in the North West is assisting a family whose father had become completely dependent following a number of severe strokes. He is completely immobile, unable to perform any tasks unaided, unable to communicate and totally

⁸³ Q304

⁸⁴ Q304

⁸⁵ Q304

⁸⁶ Q163

reliant on 24 hour nursing care. The family were advised that their father would have to be placed in a nursing home, and were told that his home would need to be sold to fund his care. The family received no information about the assessment process, or even whether their father had received a continuing health care assessment.

When investigating further, it was revealed that their father had never been provided with a continuing health care assessment. A joint assessment between the NHS and social services had been carried out, resulting in their father being assessed as being eligible for medium rate nursing care. The family was totally unaware of this, and had never been informed. The family has requested a continuing health care assessment and is awaiting a new decision.⁸⁷

112. We were also told of several similar cases. Barbara Pointon said quite simply that, in the case of her husband,

I went for five years without knowing it existed. If you do not know it exists, then you cannot apply for it.⁸⁸

113. Pauline Thompson of Age Concern described the following story:

A friend of mine only last week was telling me, “my Mum has got to go into a nursing home next week” – she was in hospital. I said: “Have they done a continuing care assessment?” She looked at me blankly. “Do you know how much nursing bands she is going to get?” Again, she looked at me blankly. So I put down a few questions to her – “you must ask this, this and this before you agree that your Mum can go into a nursing home” and she now has continuing care, but it was only because she showed them the e-mail I had sent her and said, “Should I be asking for continuing care?” The social worker said: “Oh, yes, I think perhaps you might.” It would not have been raised otherwise.⁸⁹

114. Ms Thompson went on to argue that the culture of the NHS does not promote easy access to assessments:

If you ask for continuing care, we find that people are put off right from the very beginning – “oh, nobody gets it in this area; you have to be nearly dead to get it”. So right from the start you are working from a system whereby you might find that in that case you will not bother. It is an attitude ... it is a mindset at the moment within the NHS that they are there to deal with acute services, and continuing care is something else really.⁹⁰

115. Mrs Pointon suggested that it would help if a single professional was designated “whose responsibility it is to tell all families about the existence of continuing care.”⁹¹

⁸⁷ CC15

⁸⁸ Q97

⁸⁹ Q108

⁹⁰ Q98

⁹¹ Q97

116. We were shocked to hear that some patients and their relatives are not offered any form of assessment for continuing care, and subsequently do not receive assessments because they are simply unaware that continuing care funding exists, and that they might be entitled to it. We do not think that the onus should be on patients or their relatives or carers to request an assessment for continuing care:– all patients with continuing needs should be offered an assessment automatically, before they leave hospital. In developing its national framework for continuing care, the Government must take steps to ensure that this happens. It should also give consideration to establishing a system whereby every care setting, including NHS acute hospitals, primary care and private nursing or residential homes, should have a nominated individual whose responsibility it is to proactively identify all those who may need a continuing care assessment and notify the appropriate PCT, which should have a duty to arrange for an assessment (or re-assessment) within a specified timescale.

Inequities arising from different application of criteria

117. Several submissions have indicated that, even if criteria for continuing care are consistent, approaches to assessment and application of those criteria are not, leading to even wider variation. When we discussed the concept of 28 different SHAs having different eligibility criteria, Denise Gilley of County Durham and Tees Valley SHA told us that that view in fact over-simplified the situation: “it is to do with the assessment process. It is not to do with 28 strategic health authorities, with all due respect, but the number of primary care trusts and their partners, the social services departments.”⁹² Elaine McHale, who is the Director of Social Services and Health for Wakefield Metropolitan District Council as well as representing the ADSS, reported that despite a good partnership approach between the local authorities within her SHA area, “there are differences in its application, even though the eligibility is the same.” She went on to describe how a group of representatives in her area still have to examine cases “to see why in Bradford you might get continuing care with this case but, if you applied for it in Wakefield, you would not.”⁹³

118. Help the Aged argued that in some places there was anecdotal evidence to suggest that the methods being used to carry out continuing care assessments “raise the threshold for eligibility even beyond that set out by the criteria themselves.”⁹⁴

119. Anne Williams described the situation from a patient’s view point:

Every PCT, even though they have got the same strategic health authority criteria, have interpreted it very differently. Every professional on the ground then interpreted that slightly differently, and it is the one area where the public have the least comprehension on how it is working. It is very difficult, especially if a couple may have a parent each who is in need of continuing care, who live literally up the road from each other but come within two different PCT areas, and they cannot

⁹² Q16

⁹³ Q6

⁹⁴ CC28, para 2.4

understand at all why one will be eligible and the other one who in their minds is more ill and therefore needs more care cannot get it. You cannot explain it.⁹⁵

120. According to Martin Green of the English Community Care Association, when homes take residents from more than one PCT or even different SHAs, it is very likely that there will be an inconsistency of assessment between different PCTs, meaning that some people are receiving high levels of funding and some are receiving much lower levels of funding, even although they have the same needs. This creates serious difficulties for care homes, which will have to find the resources to meet the needs of all residents, regardless of the funding they are receiving.⁹⁶ As Mr Green explained, this inconsistency in assessment could lead to care homes ‘cherry-picking’ patients from certain areas, who were likely to have received a more generous assessment:

As the demographics change, and particularly as there are more people with very high dependencies because of Alzheimer’s disease and dementias, there will be even more pressure on beds. The inconsistencies inherent in the processes around assessment will then lead to some people saying “no, I am not going to have your patient in this establishment because somebody else does a better assessment process and is prepared to pay more for more intensive care”.⁹⁷

121. Clearly, the first problem that needs to be addressed is the inconsistent approach to assessment. It will never be possible to ensure that the implementation of criteria is identical across the country, as Cath Attlee of Hounslow PCT argued: “You are not going to eliminate the element of professional judgment, even if you have standard criteria across the country. Every clinician will interpret slightly differently, and practice is changing all the time.”⁹⁸ However, with a single approach to assessment, these inconsistencies can be minimised. Both our witnesses and our written evidence called for the Government to develop a national system of assessment, with a single set of documentation, to ensure that all assessments are carried out using the same nationally approved processes.

122. We have recommended the development of a single set of national criteria, which should go some way towards ensuring that patients have the same entitlement to continuing care funding in all parts of England. However, a single set of eligibility criteria are only part of the solution, because, as our witnesses pointed out, even when using the same SHA criteria, inconsistencies have still emerged with different PCTs interpreting the same eligibility criteria differently because they have followed different assessment processes. It is therefore imperative that the Government underpins its national criteria with a national standard assessment methodology, building on current best practice to develop a universal, standardised assessment process backed up by a single set of documentation which will be applied by all Strategic Health Authorities, PCT’s and NHS Trusts, in conjunction with local authority social services departments.

⁹⁵ Q100

⁹⁶ Q178

⁹⁷ Q179

⁹⁸ Q9

Professional input into the assessment process

123. The Ombudsman made the damning observation that in over half the cases her Office examined, assessments had been inadequate:

In more than half of the cases my Office examined we found that the assessments had not been carried out properly. The problems included poor quality clinical input to both assessment and decision making, inadequate documentation, failure to consider changes in a patient's health care needs over time, and lack of involvement of, and poor communication with, patients, carers and relatives.⁹⁹

124. In oral evidence, Colin Houghton of the Ombudsman's office described some of the poor assessment practice which he had come across:

Where people have psychological needs – I saw that you had Barbara Pointon here last week – sometimes psychological needs are not taken into account. Other examples are where, for example, someone will go into a nursing home, look at all the nursing home notes, prepare a summary of their view of what that health care portrayal presents, and then present that to the decision panel. The decision panel will only have that summary and not the full notes, so someone is already interpreting something before it ever gets to the panel. Those are some examples.¹⁰⁰

125. It is clearly crucial that the appropriate people are involved in carrying out assessments. While under the SAP every older person is entitled to a full multidisciplinary assessment, including a representative from every discipline involved in their care, all too often, assessments are carried out by people with insufficient expertise, particularly given the pressure on staff to free up beds in acute hospitals:

In a large hospital setting there will be many, many beds taken, with bed-blocking and all the rest of it, so there is a lot of pressure on the ground for the front-line staff to get this done. Sometimes ... two people will make the decision. The doctor's input and other professionals will come in at an after date, but that person has been moved out of that hospital and into a situation where there is no nursing care, and to get them out of the hospital pretty quickly.¹⁰¹

126. Geriatricians can also make a key input into assessments, but again, very few people get a full assessment from a geriatrician.

127. One of the Ombudsman's key recommendations was better training, to ensure those carrying out the assessments have a good understanding of the processes, and also the development of increased capacity, to ensure assessments can be carried out promptly.¹⁰²

128. In developing its national assessment framework, we recommend that the Government should include clarification about which professionals should be involved in carrying out assessments for NHS continuing care. In line with the Ombudsman's

⁹⁹ CC23, para 6

¹⁰⁰ Q224

¹⁰¹ Q107

¹⁰² CC23, para 7

suggestion, the Government should ensure that there are sufficient numbers of trained staff to carry out assessments promptly and professionally. The Government should also develop a national training programme, which all those involved in carrying out assessments should complete.

Review and reassessment

129. People's needs, and particularly those of elderly people, can change frequently. Much of our evidence highlighted difficulties in getting both RNCC and continuing care assessments reviewed promptly. According to Ms McHale this does not always happen in practice:

There is not a proper process for review. If you are in a nursing home and you are on the high banding of nursing free-funded care, then if you then deteriorate into continuing care, potentially there is not the opportunity automatically to have that resolved. There are issues about that.¹⁰³

130. Ms Attlee argued that reviews ought to be annual, and indeed that is the minimum standard set out by the SAP:

There is a built-in expectation that a nursing review would be undertaken every year and at any point, either the inmate or the nursing home can trigger a continuing care assessment. Again, it may be about practice not reflecting policy.¹⁰⁴

131. We were also told that in many circumstances annual reviews are not sufficient, with people's needs often changing far more frequently.¹⁰⁵

132. The national standard assessment methodology must include flexible provision for regular review, placing a specific requirement on the organisation providing care to trigger a review whenever needs change. At the very minimum, all patients should be reviewed every year, but there must be scope for reviews to be triggered as soon as they become necessary, and for these to be carried out flexibly and promptly.

Patient and carer involvement and information

133. A key concern in our evidence was that patients and carers lacked both information about, and involvement in, the assessment process. According to John Wheatley of Citizens' Advice:

It is clear to us ...that people do not get enough clear information about what the process is, what their rights are for reviews, and how the review processes are carried out; there does ... need to be an information strategy for people.¹⁰⁶

¹⁰³ Q24

¹⁰⁴ Q26

¹⁰⁵ Q181

¹⁰⁶ Q94

134. We were told by Ms Peck that patients, relatives and carers do not normally see the assessment that goes to their local funding panel.¹⁰⁷ However, according to Barbara Pointon, from a carer's point of view this is indefensible:

We are the people who see most of the patient and know their needs intimately ... I found the health assessments that were done of my husband – one of them had 14 major inaccuracies in it because I had not seen the assessment before it was sent in to the panel, which then decided that Malcolm's care was social; but missing from the assessment was the fact that he had frequent fits, so how could his care be stable?¹⁰⁸

135. The Deputy Ombudsman told us that “including the families/the carers is very helpful and would certainly represent good practice.”¹⁰⁹

136. Patients, carers and relatives should have automatic access to detailed information about the assessment process, both before it begins, and during the process itself, and we recommend that the new national standard assessment methodology includes specific requirements in this area. Not only is full information-sharing crucial to ensuring transparency, and useful in helping patients, carers and relatives understand how decisions were arrived at. Patients, carers and relatives can also provide a failsafe system for ensuring there are no inaccuracies in assessments, as they are likely to have a better understanding of their own or their loved one's condition than any professionals.

RNCC overlap

137. We have already discussed the difficulties caused by the fact that eligibility criteria for NHS continuing care and for high band RNCC are virtually indistinguishable. A further problem related to the RNCC is the practical application of the criteria. According to our evidence, many people treat RNCC as a ladder of eligibility which leads upwards to NHS fully funded continuing care. In fact, this should be inverted, with the question of eligibility for continuing care being asked *before* RNCC is considered. The guidance issued by the Department of Health in August 2001 indicates that a full assessment of need should have been carried out before any determination of RNCC is undertaken. All possible care pathways will have been considered *including* whether the person's needs meet the criteria for NHS continuing care. It is only when it is decided that they do not *and* that their needs can best be met in a care home providing nursing care, that the RNCC determination should take place. The guidance states categorically:

Remember that the person's eligibility for NHS continuing care should be considered once assessment information has been evaluated and an appropriate care plan is being considered. If your examination of all the patient information leads you to think that in fact this person *does* meet the criteria for NHS continuing care (that is,

¹⁰⁷ Q172

¹⁰⁸ Q127

¹⁰⁹ Q215

their needs appear significantly greater than the high band of nursing need and their *primary* need is for health care) the case should be re-directed.¹¹⁰

Even this guidance, with its reference to the NHS continuing care criteria in comparison to the high band RNCC, could be open to misinterpretation.

138. Anne Williams of Citizens' Advice described how, in practice, people involved in assessments carry out the RNCC assessment first, using that system as an ascending ladder towards continuing care. This means that, if a person is assessed as requiring registered nursing care, they are denied access to consideration for continuing care funding, even though they may have significant health care needs which are not picked up by the RNCC assessment, which is concerned solely with registered nursing needs, and not with wider health care needs:

We see a lot of cases where, regardless of how many toolkits people are given or criteria, the practice still regularly occurs where people do the RNCC banding; and then, because you are not getting the highest level you do not get the continuing care. When we get involved and asked the date of the continuing care assessment, they were all done at the same time by the same people, and because you have not got the highest level of nursing care, which has been explained is very difficult – we had a client who was unfortunately in the very last stages of the Parkinson mask, which means that their condition is very, very stable and they are very, very rigid, so they are not qualified for the highest level of nursing care. The fact that that person has huge nursing care needs means that they do not qualify for the highest level of nursing care because they are not unstable, and therefore that particular client was refused continuing care. When we got involved and started to ask when they started to do the continuing care assessment - luckily it has now been awarded.¹¹¹

139. According to Mrs Pointon, one reason for this may be lack of understanding amongst the people carrying out the assessments:

I would say anecdotally that although I asked Malcolm to be assessed against the continuing care criteria twice he was assessed against the RNCC, and so even when you ask for it – I think there is confusion among some of the professionals actually, who do the assessments.¹¹²

140. Ms McHale also agreed that there was a strong need to “re-emphasise the requirement for the continuing care assessments to be done, first and foremost.”¹¹³

141. Despite the Department of Health’s guidance that assessment for continuing care must always be carried out first, and RNCC assessment only carried out if the patient is deemed to be ineligible for NHS continuing care, the evidence presented to this inquiry indicates that in practice RNCC assessments are often carried out first, with the result that patients may not get the funding they need because they have been inappropriately

¹¹⁰ Department of Health, *NHS funded nursing care: Practice guide and workbook*, 2001

¹¹¹ Q105

¹¹² Q108

¹¹³ Q25

assessed through the RNCC framework alone. In the light of our previous recommendations concerning the confusion and overlap between the separate systems for continuing care and RNCC, the Government must develop an integrated system which will eliminate much of this confusion. The national standard assessment methodology must provide detailed guidance on how, and in what order, patients' needs should be assessed.

Monitoring of the application of criteria

142. To ensure that new national criteria are applied fairly and consistently across the country, that all those who need assessments have access to them, and that assessments are carried out to a high standard, monitoring will be crucial, as Denise Gilley told us:

It is about monitoring them and their consistency of decision-making and making sure that people who are assessing and people who are deciding are doing that in a consistent and transparent way.¹¹⁴

Ms Attlee agreed:

You have a multidisciplinary team doing the assessment; another multidisciplinary panel validating that assessment locally; and then a strategic health authority-wide or higher level authority validating across the board, so that you are constantly doing that cross-checking ... It is important that in any system we implement you build those checks and balances in.¹¹⁵

143. In oral evidence to us, SHAs told us they had some systems already in place to monitor decision-making in this area, but they seemed to be at a relatively early stage in development, and to vary between regions.

We do have a software programme...It does exist and it does work but it does not give us the level of data extraction that we would like. It is the beginnings of something.¹¹⁶

We are probably not quite at the stage of having the electronic data but we are looking at similar issues around placement and getting the financial information ... We also have the SHA panel which sees cases. We have been using the panel's test for consistency of decision-making across primary care trusts. We are also looking, as part of the training for assessors, at possibly assessing sample anonymised cases to check that the same results come out.¹¹⁷

144. Monitoring is vital to ensure consistent decision-making in continuing care assessments. However, monitoring systems do not yet appear to be very well developed, and we urge the Government to ensure, as part of the national framework for continuing care, that robust, consistent systems are put in place throughout the

¹¹⁴ Q16

¹¹⁵ Q9

¹¹⁶ Q35 (Denise Gilley, County Durham and Tees Valley SHA)

¹¹⁷ Q35 (Michael Young, North West London SHA)

country to monitor the implementation of the new national eligibility criteria and the national standard assessment methodology.

PCT panels and funding decisions

145. The division of health and social care funding inevitably gives rise to tension between PCTs and Local Authorities over who funds care. This issue caused our witnesses considerable concern. One Local Authority guidance note stated: “From a social services perspective, it is not about merely cost shunting on to the NHS. What we are trying to do is to ensure that our monies are targeted at those to whom Social Services are responsible for providing a service.”¹¹⁸ By the same logic, although it is unlikely to be stated policy, PCTs are obviously financially advantaged if people are not assessed as requiring fully funded NHS continuing care. Ms Attlee acknowledged that financial constraints can have a bearing on the process: “I am not saying it never happens. Certainly PCTs have financial problems and that has a bearing effectively on how things are implemented.”¹¹⁹ According to the ADSS, this is a real problem:

There is a big element of difficulty facing primary care trusts in balancing their budgets and dealing with the demands that continuing care can make. We have done some surveys of local authorities. We know there is at least one PCT which has a cap on how much per person they will give towards care.¹²⁰

146. Our evidence suggested that some, although not all, PCTs operate funding and review panels to approve and review decisions on funding for continuing care. According to the RCN, PCT panels frequently make decisions on cost rather than clinical grounds:

Once a nursing assessment is carried out to determine a patient’s eligibility for NHS continuing care funding, recommendations are made to a funding panel. RCN members advise us that in some instances, panels are overturning recommendations made by nursing staff because of local financial constraints. Our members are concerned that access is being driven by budgetary concerns rather than need which is both demoralising for staff and upsetting for patients. The RCN has been advised by a local practitioner that in one locality in the East of England social services staff are advised not to apply for funding for their clients as it is not available. Elsewhere, experienced clinicians report that their clinical assessment is overturned by panels with no explanation being offered to either the clinician or the patient.¹²¹

147. The Minister confirmed that the development of a national framework will address the role and constitution of PCT review and funding panels.¹²²

148. Much of our evidence concerned PCT review and funding panels, and indicated that, where these exist, decisions are often driven by budgetary concerns rather than patient need, and clinical assessments are overturned without explanation. This should

¹¹⁸ CC12B, Hampshire Social Services

¹¹⁹ Q29

¹²⁰ Q27

¹²¹ CC21, para 3.6

¹²² Q313

not be allowed to continue, and we are pleased that the Minister confirmed that the role and constitution of funding panels will be addressed within the forthcoming national framework for continuing care. While there is clearly a need for PCTs or SHAs to review local decisions to ensure consistency and quality of assessment, we question the need for a PCT panel to validate all eligibility decisions, as we are concerned that panels will serve a gatekeeping function to manage demand on PCT financial resources. Eligibility criteria and related assessments must be based on the needs of the individual, and must not take account of the financial consequences. We therefore recommend the new national framework should stipulate that PCT panels must only be used to assess cases where patients have appealed against a decision, not as a final process through which all clinical assessments must be ratified, and that the membership of continuing care panels should include appropriate clinical expertise, rather than clinical decisions being made by Directors of Finance.

7 Retrospective review of funding decisions

149. Following the Ombudsman’s recommendation in February 2003 that the NHS should carry out retrospective reviews of continuing care funding decisions, according to the Department’s figures, nearly 12,000 retrospective reviews have been carried out, with 20% of these resulting in partial or total NHS funding for the patient. The Department of Health has stated that the NHS expects to pay a total of £180 million in restitution.

The Ombudsman’s concerns about the review process

150. In a follow-up review published in December 2004, the Ombudsman made several criticisms of the process of reviewing past funding decisions. The first of these was that there had been an inconsistent approach to reviews:

In April 2003 the Department of Health issued a suggested procedure for carrying out the retrospective reviews. Some primary care trusts were unaware of it, local expertise in continuing care was sometimes limited and support from the Department was often lacking. Many NHS bodies made considerable efforts to carry out the reviews robustly and fairly. But the complaints to us show that there was significant variation in the way NHS bodies approached reviews and that in some cases they were poorly carried out.¹²³

151. The Ombudsman went on to argue that “adequate explanations of the purpose of the reviews, and training for assessors and panel members, were either patchy or non-existent”.¹²⁴

152. The Ombudsman also highlighted delays in the process which were caused by insufficient NHS capacity to carry out the reviews within the Department’s initial timescale. In oral evidence, Trish Longdon, the Deputy Ombudsman, told us:

We were concerned that we were misled as to the timeliness of reviews – and, indeed, we then asked complainants to rely on those commitments that were given. So we share your concern that commitments were given and we therefore then said to a complainant, “You should go back to your SHA and it will all be completed by” – December/April/July – and therefore we are very, very concerned that we had assurances on which we relied which affected people.¹²⁵

153. According to the Ombudsman, “local capacity to deal with the demand for retrospective reviews was severely restricted in places, contributing to considerable delays in starting on them.”¹²⁶ Age Concern also told us that where people had been awarded a

¹²³ The Health Service Ombudsman for England, *NHS Funding for Long Term Care – Follow up report*, HC 144, December 2004, pp1-2

¹²⁴ The Health Service Ombudsman for England, *NHS Funding for Long Term Care – Follow up report*, HC 144, December 2004, p1

¹²⁵ Q246

¹²⁶ The Health Service Ombudsman for England, *NHS Funding for Long Term Care – Follow up report*, HC 144, December 2004, p1

retrospective award, there have sometimes been problems with delays in the payments being made.¹²⁷

154. Another key concern about the retrospective review process centres on the lack of communication with patients and relatives:

Variable communication with, and involvement of, patients and relatives: some NHS bodies have made considerable efforts to communicate effectively throughout the process. Others have done less than the bare minimum, for example sending one-paragraph rejection letters with little reasoned explanation of decisions.¹²⁸

155. Citizens' Advice gave a very worrying example of the difficulties faced by patients seeking restitution:

A CAB adviser in the south west who accompanied a client to a review, commented that it felt as if the balance was firmly tipped against the client. There was no guidance to help people interpret the criteria so that they knew what were the key points of their case which they should emphasise. In addition the local review officer had prepared a written report which was copied to the eight panel members but not to the patient until the adviser requested it.¹²⁹

156. We are concerned at the reports we have received from many of our witnesses identifying significant problems with the retrospective review process. These included delays, poor communication with patients and relatives, and lack of Government support and guidance for those carrying out the reviews. We urge the Government to ensure that, in any future reviews, lessons are learnt from shortcomings in the review process identified by the Ombudsman's 2004 report and the independent review commissioned by the Department of Health.

Has every case that should have been reviewed been identified?

157. In addition to inconsistency, delays, and poor patient involvement in the retrospective review process, our evidence suggests that all those potentially entitled to restitution may not, in fact, have been offered a review. This difficulty stems from the fact that, rather than proactively trawling their records for people who might have been wrongly assessed and making contact with them, SHAs relied on local publicity campaigns to encourage people who might be entitled to a review to contact them.

158. The independent review quotes a respondent as saying that "the publicity machine has worked extremely well for those who know how to use it and how to write letters".¹³⁰ A similar comment was made by the Royal College of Physicians of Edinburgh: "We would echo the experience that the articulate and intelligent are more likely to obtain 'free' care

¹²⁷ CC29, para 2.4

¹²⁸ The Health Service Ombudsman for England, *NHS Funding for Long Term Care – Follow up report*, HC 144, December 2004, p2

¹²⁹ CC15

¹³⁰ Para 3.43

through their advocacy and those who are most disadvantaged are least likely to benefit from the review system.”¹³¹

159. Denise Gilley of County Durham and Tees Valley SHA told us that her organisation had used local advice agencies, and also that in her area word of mouth and local networks had worked well:

We did have one instance where somebody who was a regular attender at the local working men’s club then told everybody about the payment, and the primary care trust in Easington were then contacted by the club’s secretary, who asked if we would like to look at all of these others. The point I am making, apart from the fact that it is amusing, is that it did pick up some other people who were family people who should have been funded.¹³²

160. However, although some local organisations have been very effective in informing people of the review, they do not guarantee universal coverage: Ms Gilley told us that the SHA had established links with the Easington working men’s club but, “obviously, we were unable to replicate that across all of the working men’s clubs in County Durham and Tees Valley.”¹³³

161. Age Concern told us that it had “concerns about the robustness with which some strategic health authorities have trawled”,¹³⁴ and these concerns were echoed by the Ombudsman:

We have some concerns about everybody who needed to know having been captured by the publicity.¹³⁵

162. When we put this to the Minister, he told us that he was satisfied that the trawl arrangements had been thorough enough:

Certainly we did ask strategic health authorities to carry out a trawl of people who they think might have been wrongly assessed and they should have done it automatically. I would be surprised if we have caught everybody in the net, but we tried ... instructions were given to carry out a trawl to try and do it as well as we could, but this is an imperfect world.¹³⁶

163. We were concerned by many witnesses’ doubts that SHAs’ review processes had succeeded in identifying all those who might have been wrongly assessed, and in particular that publicity campaigns had favoured the articulate and well informed. When we put this to the Minister, he responded that SHAs had ‘tried’ to do the trawl as well as they could, but that ‘this is an imperfect world’. The Government should have instructed SHAs to proactively search their records to identify potential cases

¹³¹ CC11

¹³² Q74

¹³³ Q74

¹³⁴ Q126

¹³⁵ Q201

¹³⁶ Q335

themselves, rather than relying on publicity and word of mouth to encourage claimants to come forward. We would urge the Government to endeavour to continue to identify people who might have been affected.

Problems with record keeping

164. An enduring theme throughout our evidence was the poor quality record keeping, and in some cases, absence of records. This has caused considerable problems in carrying out retrospective reviews. According to the independent review, the quality of individual case records varied from very bad to excellent. Instances were frequently cited where records were undated, unsigned, or contained nothing of any relevance to the needs of the resident, and where residents' notes were frequently in the wrong files. In a few instances there were situations in which records were not contemporaneous and had clearly been created for the purpose of the review.¹³⁷

165. Michael Young of North West London SHA argued that the lack of records, and difficulty in accessing records had not been anticipated by SHAs.¹³⁸ Cath Attlee of Hounslow PCT told us that although problems with record keeping were not evident everywhere, there were “examples across the board” in all types of care settings, not only residential care homes.¹³⁹

166. Anne Williams of Citizens' Advice also argued that in carrying out the reviews, some SHAs had been inflexible in the types of records they would accept as evidence, refusing to accept evidence from carers, or even GPs or hospitals records, and instead would accept only the “written contemporaneous records of the nursing care that was given at that time” that was prepared by the care home. As some nursing homes have closed down, this creates an impasse, where the case “just sits on a desk and it is very difficult to get it moved forward”.¹⁴⁰

167. The retrospective review process has brought to light serious shortcomings in the quality of information and record-keeping in assessments and in on-going care management. Not all records can be kept indefinitely, and we do not want to impose an intolerable burden on NHS organisations and care homes. However, clearer guidance on what should be kept and how long for is clearly needed, and we therefore recommend that the national framework for continuing care should provide detailed guidance on this. Because of the difficulties in obtaining contemporaneous nursing records, we also recommend that SHAs who are still involved in the retrospective review process should adopt a more flexible approach to the types of evidence they will consider, including carer evidence, and GP and hospital records.

Restitution or compensation?

168. SHAs told us that in accordance with Department of Health guidance, they had made restitution payments to people wrongly denied continuing care, based on the actual costs

¹³⁷ Department of Health (Henwood M), *Continuing Health Care: Review, revision and restitution*, December 2004.

¹³⁸ Q51

¹³⁹ Q49

¹⁴⁰ Qq95-96

they incurred adjusted for inflation, but not compensating them for any other losses they might have incurred, for example if people sold their homes, or had to give up jobs to care for relatives.¹⁴¹

169. However, in her memorandum the Ombudsman stated that it is her principle that “where funding was wrongly withheld, the individual, or their estate, should be put back in the position they would have been in had the maladministration not occurred”¹⁴². The Ombudsman has received many cases claiming compensation for sale of houses or for loss of earnings, and is currently taking these forward with the Department rather than with the individual SHAs or trusts involved.

170. The Minister argued that the Government’s policy was based on the approach that “would have been arrived at by the Courts”. He argued that providing people with compensation on the grounds that their house, had they not sold it, might have increased in value, could give rise to increasingly ambitious financial claims based on entirely hypothetical arguments, and also pointed out that, when people were made retrospective payments for continuing care, they were not required to pay back any benefits they received at the time, to which they would not have been entitled had they been receiving continuing care.¹⁴³

171. It is beyond the scope of this inquiry to address the question of whether people wrongly denied continuing care should be given compensation for house sales and loss of earnings as well as simple restitution for the actual money they spent. However, the Ombudsman has raised this as a serious concern expressed in a number of complaints she has received. We urge the Government to liaise with the Ombudsman on this issue to attempt to agree a common position. Where appropriate, complainants should have access to adequate legal advice.

¹⁴¹ Q56

¹⁴² CC23, para 14

¹⁴³ Q340

8 Wider issues concerning the continuing care and RNCC systems

172. In addition to concerns about eligibility criteria and their implementation, several wider issues concerning the continuing care system and the RNCC system have been raised in our evidence, which the Government must take account of in its review of continuing care. The first is that under the current system it is difficult to obtain continuing care funding for care at home, and patients cannot have the flexibility of direct payments. Secondly, we have been told that both systems have perverse incentives which promote increased dependency rather than independence. Finally, our evidence also suggests that Government contributions towards care, whether continuing care or nursing care, may not directly benefit the patient at all, and may, in some circumstances, positively disadvantage them.

Lack of flexibility in the delivery of continuing care

173. One of the advantages of the large-scale closure of long-stay NHS wards and hospitals was that it encouraged more people to live, and to be cared for, in their own homes. As the Minister pointed out, this is the preference of the vast majority of older people. Guidance has repeatedly emphasised that continuing care can be delivered in any setting, including patient's own homes. However, in practice it can prove difficult to secure full NHS continuing care funding for patients being cared for at home. Pauline Thompson of Age Concern explained the problems this causes:

There seems to be a mindset that you can only get fully-funded NHS care in a nursing home, whereas it is quite clear in the guidance that you can get it anywhere. Only last week, I had somebody who rang me up who was told that if they went into a nursing home, they would have the care package fully funded by the NHS, but if he went home the personal care would have to be funded by social services; therefore he would have to pay.¹⁴⁴

174. It is possible to provide NHS continuing care to people in their own homes, but it involves a creative interpretation of the law. This issue was particularly highlighted by the Pointon case, where Malcolm Pointon had been benefiting from direct payments to support his highly personalised and successful arrangements for care at home, but these arrangements were then jeopardised when he was granted fully funded continuing care, as the NHS is legally unable to make direct payments. In Barbara Pointon's view, the single measure that would most improve the continuing care system would be the introduction of direct payments.¹⁴⁵ The Minister told us how health officials and local council officials had worked together innovatively to interpret existing legislation in order to enable Mrs Pointon to provide for her husband's care as she had done before he became eligible for NHS continuing care. According to the Minister, "the question is whether we should be

¹⁴⁴ Q93-94

¹⁴⁵ Q92

expecting people to work innovatively in order to get round the law, or whether we should just change the law”.¹⁴⁶

175. We recommend that within its review of continuing care, the Government should take steps to enable continuing care to be delivered more flexibly than is currently the case. Care should be organised according to a person’s needs, and the funding system should recognise that an institutional setting is not the only, and may not be the best, place for these needs to be met. The Green Paper on Adult Social Care attaches particular importance to the development of direct payments and to giving people greater autonomy in making care arrangements. We welcome this, and urge the Government to consider ways in which the care arrangements supported by direct payments can be maintained if people are re-assessed as having health care needs.

Perverse incentives towards increased dependency

176. Several submissions drew attention to the perverse incentives within the RNCC system. The RCN argued that a major problem with the current system is that it may in fact promote increased dependency:

Similarly there is a need for the eligibility criteria themselves to be reformed so as to reflect a change in emphasis to rehabilitation and re-enablement. Currently, the criteria focus on the level of a patients’ dependency. This creates a perverse incentive whereby if a patient’s condition improves, the level of funding available decreases. Best practice in nursing older people is based on a rehabilitation/re-enablement approach to care. Criteria which emphasise rehabilitation and re-enablement would ensure that patients receive nursing and therapy services which aim to promote abilities, enhance quality of life and in the longer term may well result in the need for less care services.¹⁴⁷

177. If a home succeeds in achieving a degree of rehabilitation for residents and improves their quality of life, it will often find itself financially penalised when residents who have regained some independence subsequently have their RNCC banding revised downwards, reducing the payments made to the home. This acts as a perverse incentive, and may deter homes from providing intensive rehabilitation to patients. If a patient then regains independence and their RNCC funding is reduced, their care home may consequently devote less nursing time to them, when actually ongoing high quality nursing care is needed to maintain their independence.

178. John Pye of the RCN expanded on this in oral evidence, drawing on examples from his own practice:

We have a number of patients who we have assessed using the RNCC and those assessments were made on the wards in hospitals and were high bands. We placed them into our local nearby nursing homes where they have very good care, and their dementia has been treated accordingly. They are now improving substantially, and we have now gone in and re-banded those patients and given less finance to the

¹⁴⁶ Q322

¹⁴⁷ CC21, para 5.4

nursing home to look after them, which has a massive detrimental effect both upon the individuals themselves potentially but also on the business of the nursing home to try and maintain the same level of standards which they wish to have.¹⁴⁸

179. When we put this to the Minister, he seemed unaware of the specific problem with the RNCC, although he recognised that one of the problems of the wider social care system was that it promoted dependency:

Chairman: The RCN said, “Currently the criteria focus on the level of a patient’s dependency. This creates a perverse incentive whereby if a patient’s condition improves the level of funding available decreases.” Is that something that you are conscious of and is it something that you might be able to address?

Dr Ladyman: I had not thought about it in those terms, but what I am absolutely committed to is helping people maintain their independence. I believe that the way we have adult social care and some aspects of health care structured in this country at the moment encourages dependency instead of independence.¹⁴⁹

180. We were deeply concerned to hear that the RNCC framework has inbuilt perverse incentives which reward dependency rather than rehabilitation and independence. Homes that are able to provide nursing care which successfully achieves rehabilitation for residents and improves their quality of life often find that they are penalised, as those patients then have their RNCC bandings reduced, and consequently payments to the home are reduced. This fails to recognise that it is precisely the level and quality of nursing input which enables individuals to be maintained at a higher level of independence and that this is jeopardised by reducing the RNCC payment. Conversely, homes that fail to provide sufficient nursing inputs to improve the health and well-being of residents will often have them assessed at higher bandings because of their resulting dependency, which may in fact reward poor care practices. The Minister told us that he was “absolutely committed to helping people maintain their independence”. If this is the case, the Government must fundamentally redesign the RNCC and continuing care funding systems so that they have inbuilt incentives which reward high quality care rather than penalising it.

Does the contribution benefit patients?

181. During our inquiry into Delayed Discharges, the then Minister (Jacqui Smith) and the Chief Inspector of Social Services (Denise Platt) both suggested that the money provided through the RNCC should directly benefit the residents for whom it was intended.¹⁵⁰ However, our evidence suggests that when people are awarded RNCC payments, some homes then increase their charges to residents by sums at least equivalent to the RNCC payments, leaving the resident no better off. Pauline Thompson of Age Concern gave us an example of a man whose wife was moving into a care home who was initially told that the

¹⁴⁸ Q131

¹⁴⁹ Q330

¹⁵⁰ Health Committee, Third Report of Session 2001-02, *Delayed Discharges*, HC 617 – II, Q736, Q155

fee would be £450 a week, and then when it transpired that she would be receiving RNCC funding of £125 per week, the fees went up by about £125.¹⁵¹

182. The Minister told us he had “no doubt” that “some nursing homes have put their fees up in order to exploit self-funders”.¹⁵² However, he stated that as “Nursing care is delivered free by the National Health Service and we reimburse nursing home owners for it”, no one should be charged for nursing care, and patients and their relatives should ask for itemised bills to ensure that they are not being charged.

183. In fact, the RNCC band payments, which are established nationally, do not directly relate to the nursing care needs of an individual, or their actual costs. The bands have no relationship to the amount of time a registered nurse will actually need to spend with an individual, and also have no bearing on the nurse staffing levels required by the Commission for Social Care Inspection (CSCI) as a condition of registration of the home. Independent studies have demonstrated that across England as a whole, the average gap between actual fees paid to homes, including the RNCC element, and the fair fee for homes which are fully compliant with CSCI staffing regulations, is of the order of £127 per week for nursing care.¹⁵³

184. It follows that the additional costs of nursing care must somehow be recovered by care homes. The Minister’s comment that no one should be charged for nursing care does not adequately reflect the current realities of the situation. Either the real costs are shown on an itemised account, or they are included under euphemisms such as “extra – personal care”. As Martin Green of the English Community Care Association told us, “we need to get this assessment process really clear so that there is a robust and accountable approach for both the care needs, but also what those care needs cost”.¹⁵⁴

185. There is also anecdotal evidence to suggest that if a self-funding resident in a care home becomes eligible for continuing care, because of current rates of NHS continuing care funding, the home may face a drop in the fees paid and the resident may have to move to less expensive accommodation, or be asked to top up the NHS contribution to their care costs. Ms Thompson described the problem to us:

We have had people who were told – because there is no choice of accommodation in the NHS in the same way as there is in the social services clients – when they were first thinking about asking whether or not they should get full funding, that they will not be able to stay in the same home. That, I find, really worrying because it meant that some people were still paying for their care who could probably well be being fully funded who have to decide that because of this risk of them having to move they will not apply for it. I have had cases where the person has been found to be needing full funding, and the particular home was more expensive than the NHS was prepared to pay¹⁵⁵

¹⁵¹ Q122

¹⁵² Q331

¹⁵³ Joseph Rowntree Foundation: Laing and Buisson, “Calculating a Fair Price for Care”, May 2004, p ix

¹⁵⁴ Q184

¹⁵⁵ Q111

186. If this is happening, it could also potentially lead to care homes being less willing to seek continuing care assessment for residents if their condition deteriorates and their needs increase.

187. Despite the fact that Ministers have claimed that the value of the RNCC should be passed on to residents, we have received evidence which indicates that homes habitually increase their charges to residents by sums equivalent to the RNCC payments, which leaves the resident no better off. We urge the Government to take positive steps to ensure that the value of the RNCC payment is passed on to residents; it is unacceptable for Ministers to state that this should not be happening but to do nothing to prevent it.

188. In addition to this, we have also received anecdotal evidence suggesting that if a self-funding resident in a care home becomes eligible for continuing care, because of current rates of NHS continuing care funding, the home may face a drop in the fees paid and the resident may have to move to a different care home, or be asked to top up the NHS contribution to their care costs. Not only does this present huge upheaval for residents, potentially forced to move from familiar surroundings to a different care home which is not their first choice, it could also mean that care homes are less likely to request continuing care assessments for their residents (particularly for those who are self-funding) if their condition worsens. We recommend that, as part of its review of continuing care, the Government investigates this apparent perverse outcome of its continuing care policy.

9 Conclusions

189. The funding of long term care is a policy area which has, for over ten years, been characterised by confusion, complexity and inequity. Despite the considerable investment by Government in recent years in researching, reviewing and changing systems for the funding of long term care, it seems we are no closer to a fair and transparent system that ensures security and dignity for people who need long term care, and which promotes their independence.

190. The artificial barriers between health and social care lie at the heart of the problems surrounding access to continuing care funding, and we believe that it will be impossible to resolve these problems without first establishing a fully integrated health and social care system. We have therefore recommended, as this Committee and its predecessor Committees have done on numerous previous occasions, that the Government removes the structural division between health and social care.

191. Recognising that this radical reorganisation will take time, we have also made a number of recommendations for the Government's forthcoming national framework for NHS continuing care. The framework should include:

- the establishment of a single set of national criteria for continuing care, which takes account of psychological and mental health needs as well as physical, and which must be fully Coughlan-compliant
- the integration of the two parallel systems for funding continuing care and nursing care, as overlap is currently causing major confusion
- the establishment of a national standard assessment methodology to ensure assessments against national criteria are carried out robustly and uniformly across the country, supported by a national training programme
- the redesigning of the system for funding continuing care and nursing care, so that rather than rewarding dependency, as the system currently does, the system has inbuilt incentives which reward high quality care and promote rehabilitation and independence
- the introduction of greater flexibility in funding for NHS continuing care, to enable people to be cared for more easily in their own homes, where that is their preference

Conclusions and recommendations

1. In its forthcoming review of the system of NHS continuing care funding, it is vital that the Government draws on the views and experiences not only of NHS bodies and local authorities, but also of patients, carers and professionals. We therefore recommend that the Government's review of continuing care funding arrangements take the form of a full, formal public consultation, in line with Cabinet Office recommendations. (Paragraph 21)
2. In recent years, in inquiries addressing as diverse a range of issues as the health needs of children and young people, inappropriate use of NHS acute beds, elder abuse and care for the terminally ill, this Committee and previous Health Committees have time and again been confronted by the problems caused by the current division of systems for funding and providing health and social care. Nowhere are these problems more evident than in the area of funding for continuing care, an area in which confusion has reigned for over ten years, resulting in frustration for health and social care professionals, and suboptimal care and financial hardship for some of our most vulnerable populations. (Paragraph 40)
3. In practice the boundary between the two services has shifted over time, so that the long term care responsibilities of the NHS have reduced substantially, and people who in the past would have been cared for in NHS long stay wards are now often accommodated in nursing homes. This means that responsibility for funding long term care has to a major extent been shunted from the NHS to local authorities and individual patients and their families. (Paragraph 41)
4. The question of what is health and what is social care is one to which we can find no satisfactory answer, and which our witnesses were similarly unable to explain in meaningful terms. The policy division between health and social care lags far behind practice in a number of areas, where, born of necessity, health and social care professionals have commendably developed innovative joint working practices. We welcome these developments and the use of pooled budgets and other flexibilities, which are beginning to break down the division between health and social care. (Paragraph 42)
5. Debates about where the boundary between health and social care should be drawn have been complicated by further debates around the definitions of 'personal care' and 'nursing care', and have led to the absurd position where carers providing complex medical support for their loved ones are denied fully funded continuing care at home because they are not registered nurses. If the same care were to be given by a registered nurse, it would be regarded as nursing care and fully funded. Barbara Pointon, caring for her husband who has Alzheimer's, argued that in her experience the struggle to establish who should fund care has eclipsed the crucial issue of the patient's actual needs. She also emphasised that from a patient and carer perspective, 'care is care is care, whether you are talking about someone who is unable to dress themselves or about palliative care'. (Paragraph 43)

6. We are convinced that so long as there are two systems operating according to quite different principles, the highly controversial issue of which patients qualify for fully funded NHS care, and which have to contribute some or all of the costs of care, will remain. We strongly recommend that the Government remove once and for all the wholly artificial distinction between a universal and free health care service operating alongside a means-tested and charged for system of social care. (Paragraph 44)
7. During this inquiry, we have heard renewed calls for personal care to be provided free of charge, which would be a way, to use the Minister's phrase, of resolving many of the difficulties arising from the boundary between health and social care "at a stroke". However, the Minister stated categorically that the Government will not reconsider this option, arguing that it would be financially "unsustainable". While we have not focussed in depth on this issue during this inquiry, we dispute the Minister's argument that funding personal care would be financially "unsustainable". It is clearly for Governments to decide their own spending priorities – however, we maintain that with political will, the resources could be found to fund free personal care. Moreover, the costs of providing free personal care need to be offset against the current administrative costs associated with policing the divide between health and social care. We recommend that debate in this area is informed by the outcome of the Kings Fund study into future social care resource requirements which is currently being undertaken by Sir Derek Wanless. (Paragraph 52)
8. We recognise that a unification of all health and social care responsibilities would require primary legislation which is not an early prospect, and we have therefore framed our subsequent recommendations about continuing care in the context of today's statutory provisions. However, we urge the Government to accept our central conclusion that removing the structural barriers between health and social care is the only way to satisfactorily address these, and a great many other problems, in the long term. (Paragraph 53)
9. The NHS has an urgent need for a single, universal set of national eligibility criteria for continuing care to end the inequities and inconsistencies that have developed as a result of the current system. It is unacceptable that in one part of the country a person with a specific set of care needs would be assessed as qualifying for fully funded NHS continuing care, while a person with identical needs living in a different part of the county would be deemed ineligible, and would potentially have to fund all or part of their care from their own means. We welcome the Minister's aim of addressing this problem, and we welcome his conviction that the current review will result in the development of a single set of national eligibility criteria. However, he was not able to give us a categorical assurance on this point. A single, national set of eligibility criteria for NHS continuing care is crucial to ensure coherence and equity, and we urge the Government to ensure that a single set of national eligibility criteria is developed. (Paragraph 69)
10. We are concerned that it has taken so long for the Department to recognise and address the problem of inconsistent continuing care criteria. We recommend that the Department should consider its own internal monitoring processes with a view to detecting problems like this at an earlier stage in future. It also seems that an opportunity was missed, at the time of the Ombudsman's report in February 2003,

for the Department to start work on developing an urgently needed single set of national criteria. The Department ought to have acted sooner to develop a single set of national criteria, and we recommend that this work be completed as a priority, within the 12 month timescale indicated by the Minister. (Paragraph 74)

11. Our evidence indicates that current eligibility criteria for NHS continuing care are heavily weighted towards physical needs, to the detriment of mental health and psychological needs. It strikes us as perverse that, under current criteria, in the case of Alzheimer's Disease the further a person's illness progresses, the less likely they are to qualify for continuing care funding, even though they in fact need more intensive health care to maintain a good quality of life. Sufferers from other progressive and degenerative conditions, including Motor Neurone Disease and Parkinson's Disease, are similarly disadvantaged. We recommend that the Government's new national eligibility criteria be designed explicitly to give the same weight to mental health and psychological needs as to physical needs. (Paragraph 84)
12. It is not appropriate to produce separate eligibility criteria to cover different client groups. However, eligibility criteria must be able to adequately meet the needs of all those who need continuing care, whatever their age or diagnosis, and the Government should take account of this in developing its new national eligibility criteria for NHS continuing care. (Paragraph 88)
13. It seems to us a nonsense that two separate systems exist for assessing eligibility for fully funded NHS continuing care and for nursing care contributions as fundamentally both systems are doing the same thing, which is determining NHS funding of ongoing health care. We have heard from several authoritative sources, including the Ombudsman, that the criteria for assessing eligibility for continuing care and the high band nursing care are virtually indistinguishable from each other, causing considerable problems for those charged with applying them, and raising the possibility that, in fact, everyone who qualifies for high band RNCC should also automatically qualify for fully funded continuing care. (Paragraph 96)
14. We are surprised that these two distinct policies regarding the funding of ongoing health care have been developed by the same Department with seemingly no regard for ensuring coherence or harmony between the two systems. We urge the Government to put right this confusion and end unnecessary bureaucracy immediately. It seems to us that the simplest way to achieve this would be to integrate the two systems. If the two systems continue to co-exist, there must be clarification of the interaction between them, and we recommend simplification of the banding system. (Paragraph 97)
15. The Minister has stated that all 28 sets of eligibility criteria now operating are legal and in line with current guidance. However, we have received evidence which calls this in to question, arguing that in fact, the Coughlan case itself would have failed to meet the requirements of current eligibility criteria, either for NHS continuing care, or for high or even medium band RNCC, as Pamela Coughlan's condition was stable and predictable, although she had high level nursing care needs. Mackintosh Duncan solicitors, who specialise in continuing care law, told us that of the many sets of eligibility criteria they have seen which are currently being used, "none of those

criteria are in accordance with the Coughlan judgment”. These are very serious charges which the Government must answer. The new national eligibility criteria must be explicitly Coughlan-compliant, ensuring that all people whose primary need is for health care will receive fully funded care, even if this requires a fundamental revision of the definitions and terminology of the criteria. (Paragraph 103)

16. The Single Assessment Process (SAP) was intended to integrate assessment processes across health and social care, and to ensure that all older people were given a high-quality multi-disciplinary assessment of their needs. However, we are not convinced that implementation of the SAP system is progressing as swiftly and effectively as the Minister implied. We recommend that the Government takes steps to ensure that this is addressed. (Paragraph 110)
17. We were shocked to hear that some patients and their relatives are not offered any form of assessment for continuing care, and subsequently do not receive assessments because they are simply unaware that continuing care funding exists, and that they might be entitled to it. We do not think that the onus should be on patients or their relatives or carers to request an assessment for continuing care:- all patients with continuing needs should be offered an assessment automatically, before they leave hospital. In developing its national framework for continuing care, the Government must take steps to ensure that this happens. It should also give consideration to establishing a system whereby every care setting, including NHS acute hospitals, primary care and private nursing or residential homes, should have a nominated individual whose responsibility it is to proactively identify all those who may need a continuing care assessment and notify the appropriate PCT, which should have a duty to arrange for an assessment (or re-assessment) within a specified timescale. (Paragraph 116)
18. We have recommended the development of a single set of national criteria, which should go some way towards ensuring that patients have the same entitlement to continuing care funding in all parts of England. However, a single set of eligibility criteria are only part of the solution, because, as our witnesses pointed out, even when using the same SHA criteria, inconsistencies have still emerged with different PCTs interpreting the same eligibility criteria differently because they have followed different assessment processes. It is therefore imperative that the Government underpins its national criteria with a national standard assessment methodology, building on current best practice to develop a universal, standardised assessment process backed up by a single set of documentation which will be applied by all Strategic Health Authorities, PCT’s and NHS Trusts, in conjunction with local authority social services departments. (Paragraph 122)
19. In developing its national assessment framework, we recommend that the Government should include clarification about which professionals should be involved in carrying out assessments for NHS continuing care. In line with the Ombudsman’s suggestion, the Government should ensure that there are sufficient numbers of trained staff to carry out assessments promptly and professionally. The Government should also develop a national training programme, which all those involved in carrying out assessments should complete. (Paragraph 128)

20. The national standard assessment methodology must include flexible provision for regular review, placing a specific requirement on the organisation providing care to trigger a review whenever needs change. At the very minimum, all patients should be reviewed every year, but there must be scope for reviews to be triggered as soon as they become necessary, and for these to be carried out flexibly and promptly. (Paragraph 132)
21. Patients, carers and relatives should have automatic access to detailed information about the assessment process, both before it begins, and during the process itself, and we recommend that the new national standard assessment methodology includes specific requirements in this area. Not only is full information-sharing crucial to ensuring transparency, and useful in helping patients, carers and relatives understand how decisions were arrived at. Patients, carers and relatives can also provide a failsafe system for ensuring there are no inaccuracies in assessments, as they are likely to have a better understanding of their own or their loved one's condition than any professionals. (Paragraph 136)
22. Despite the Department of Health's guidance that assessment for continuing care must always be carried out first, and RNCC assessment only carried out if the patient is deemed to be ineligible for NHS continuing care, the evidence presented to this inquiry indicates that in practice RNCC assessments are often carried out first, with the result that patients may not get the funding they need because they have been inappropriately assessed through the RNCC framework alone. In the light of our previous recommendations concerning the confusion and overlap between the separate systems for continuing care and RNCC, the Government must develop an integrated system which will eliminate much of this confusion. The national standard assessment methodology must, provide detailed guidance on how, and in what order, patients needs should be assessed. (Paragraph 141)
23. Monitoring is vital to ensure consistent decision-making in continuing care assessments. However, monitoring systems do not yet appear to be very well developed, and we urge the Government to ensure, as part of the national framework for continuing care, that robust, consistent systems are put in place throughout the country to monitor the implementation of the new national eligibility criteria and the national standard assessment methodology. (Paragraph 144)
24. Much of our evidence concerned PCT review and funding panels, and indicated that, where these exist, decisions are often driven by budgetary concerns rather than patient need, and clinical assessments are overturned without explanation. This should not be allowed to continue, and we are pleased that the Minister confirmed that the role and constitution of funding panels will be addressed within the forthcoming national framework for continuing care. While there is clearly a need for PCTs or SHAs to review local decisions to ensure consistency and quality of assessment, we question the need for a PCT panel to validate all eligibility decisions, as we are concerned that panels will serve a gatekeeping function to manage demand on PCT financial resources. Eligibility criteria and related assessments must be based on the needs of the individual, and must not take account of the financial consequences. We therefore recommend the new national framework should stipulate that PCT panels must only be used to assess cases where patients have

appealed against a decision, not as a final process through which all clinical assessments must be ratified, and that the membership of continuing care panels should include appropriate clinical expertise, rather than clinical decisions being made by Directors of Finance. (Paragraph 148)

25. We are concerned at the reports we have received from many of our witnesses identifying significant problems with the retrospective review process. These included delays, poor communication with patients and relatives, and lack of Government support and guidance for those carrying out the reviews. We urge the Government to ensure that, in any future reviews, lessons are learnt from shortcomings in the review process identified by the Ombudsman's 2004 report and the independent review commissioned by the Department of Health. (Paragraph 150)
26. We were concerned by many witnesses' doubts that SHAs' review processes had succeeded in identifying all those who might have been wrongly assessed, and in particular that publicity campaigns had favoured the articulate and well informed. When we put this to the Minister, he responded that SHAs had 'tried' to do the trawl as well as they could, but that 'this is an imperfect world'. The Government should have instructed SHAs to proactively search their records to identify potential cases themselves, rather than relying on publicity and word of mouth to encourage claimants to come forward. We would urge the Government to endeavour to continue to identify people who might have been affected. (Paragraph 163)
27. The retrospective review process has brought to light serious shortcomings in the quality of information and record-keeping in assessments and in on-going care management. Not all records can be kept indefinitely, and we do not want to impose an intolerable burden on NHS organisations and care homes. However, clearer guidance on what should be kept and how long for is clearly needed, and we therefore recommend that the national framework for continuing care should provide detailed guidance on this. Because of the difficulties in obtaining contemporaneous nursing records, we also recommend that SHAs who are still involved in the retrospective review process should adopt a more flexible approach to the types of evidence they will consider, including carer evidence, and GP and hospital records. (Paragraph 167)
28. It is beyond the scope of this inquiry to address the question of whether people wrongly denied continuing care should be given compensation for house sales and loss of earnings as well as simple restitution for the actual money they spent. However, the Ombudsman has raised this as a serious concern expressed in a number of complaints she has received. We urge the Government to liaise with the Ombudsman on this issue to attempt to agree a common position. Where appropriate, complainants should have access to adequate legal advice. (Paragraph 171)
29. We recommend that within its review of continuing care, the Government should take steps to enable continuing care to be delivered more flexibly than is currently the case. Care should be organised according to a person's needs, and the funding system should recognise that an institutional setting is not the only, and may not be

the best, place for these needs to be met. The Green Paper on Adult Social Care attaches particular importance to the development of direct payments and to giving people greater autonomy in making care arrangements. We welcome this, and urge the Government to consider ways in which the care arrangements supported by direct payments can be maintained if people are re-assessed as having health care needs. (Paragraph 175)

30. We were deeply concerned to hear that the RNCC framework has inbuilt perverse incentives which reward dependency rather than rehabilitation and independence. Homes that are able to provide nursing care which successfully achieves rehabilitation for residents and improves their quality of life often find that they are penalised, as those patients then have their RNCC bandings reduced, and consequently payments to the home are reduced. This fails to recognise that it is precisely the level and quality of nursing input which enables individuals to be maintained at a higher level of independence and that this is jeopardised by reducing the RNCC payment. Conversely, homes that fail to provide sufficient nursing inputs to improve the health and well-being of residents will often have them assessed at higher bandings because of their resulting dependency, which may in fact reward poor care practices. The Minister told us that he was “absolutely committed to helping people maintain their independence”. If this is the case, the Government must fundamentally redesign the RNCC and continuing care funding systems so that they have inbuilt incentives which reward high quality care rather than penalising it. (Paragraph 180)
31. Despite the fact that Ministers have claimed that the value of the RNCC should be passed on to residents, we have received evidence which indicates that homes habitually increase their charges to residents by sums equivalent to the RNCC payments, which leaves the resident no better off. We urge the Government to take positive steps to ensure that the value of the RNCC payment is passed on to residents; it is unacceptable for Ministers to state that this should not be happening but to do nothing to prevent it. (Paragraph 187)
32. In addition to this, we have also received anecdotal evidence suggesting that if a self-funding resident in a care home becomes eligible for continuing care, because of current rates of NHS continuing care funding, the home may face a drop in the fees paid and the resident may have to move to a different care home, or be asked to top up the NHS contribution to their care costs. Not only does this present huge upheaval for residents, potentially forced to move from familiar surroundings to a different care home which is not their first choice, it could also mean that care homes are less likely to request continuing care assessments for their residents (particularly for those who are self-funding) if their condition worsens. We recommend that, as part of its review of continuing care, the Government investigates this apparent perverse outcome of its continuing care policy. (Paragraph 188)
33. The funding of long term care is a policy area which has, for over ten years, been characterised by confusion, complexity and inequity. Despite the considerable investment by Government in recent years in researching, reviewing and changing systems for the funding of long term care, it seems we are no closer to a fair and

transparent system that ensures security and dignity for people who need long term care, and which promotes their independence. (Paragraph 189)

34. The artificial barriers between health and social care lie at the heart of the problems surrounding access to continuing care funding, and we believe that it will be impossible to resolve these problems without first establishing a fully integrated health and social care system. We have therefore recommended, as this Committee and its predecessor Committees have done on numerous previous occasions, that the Government removes the structural division between health and social care. (Paragraph 190)
35. Recognising that this radical reorganisation will take time, we have also made a number of recommendations for the Government's forthcoming national framework for NHS continuing care. The framework should include: the establishment of a single set of national criteria for continuing care, which takes account of psychological and mental health needs as well as physical, and which must be fully Coughlan-compliant; the integration of the two parallel systems for funding continuing care and nursing care, as overlap is currently causing major confusion; the establishment of a national standard assessment methodology to ensure assessments against national criteria are carried out robustly and uniformly across the country, supported by a national training programme; the redesigning of the system for funding continuing care and nursing care, so that rather than rewarding dependency, as the system currently does, the system has inbuilt incentives which reward high quality care and promote rehabilitation and independence; the introduction of greater flexibility in funding for NHS continuing care, to enable people to be cared for more easily in their own homes, where that is their preference.(Paragraph 191)

Formal minutes

Tuesday 5 April 2002

Members present:

Mr David Hinchliffe, in the Chair

Mr Keith Bradley

Dr Richard Taylor

Dr Doug Naysmith

The Committee deliberated.

Draft Report (NHS Continuing Care), proposed by the Chairman, brought up and read.

Ordered, That the Chairman's draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 191 read and agreed to.

Summary agreed to.

Resolved, That the Report be the Sixth Report of the Committee to the House.

Ordered, That the Chairman do make the Report to the House.

Ordered, That the Provisions of Standing Order No. 134 (Select Committee (Reports)) be applied to the Report.

Ordered, That the Appendices to the Minutes of Evidence taken before the Committee be reported to the House.

Witnesses

Thursday 10 March 2005

Page

Ms Elaine McHale, Director, Social Services and Health, Wakefield Metropolitan District Council, **Ms Cath Attlee**, Director, Commissioning and Modernisation, Hounslow PCT, **Ms Yvonne Cox**, Chief Executive, Oxfordshire Learning Disability NHS Trust, **Mr Michael Young**, Developing Manager, North West London Strategic Health Authority and **Ms Denise Gilley**, Policy Leader for Older People, County Durham and Tees Valley Health Authority

Ev 1

Ms Pauline Thompson, Policy Officer, Community Care Finance, Age Concern, **Ms Julia Cream**, Head of Public Affairs, and Ms Barbara Pointon, Alzheimer's Society, **Mr John Wheatley**, Senior Social Policy Officer (Social Exclusion, Work and Welfare) and **Ms Anne Williams**, Independent Complaints Advocacy Service, Regional Co-ordinator for the North West, Citizen's Advice

Ev 17

Mr John Pye, Continuing Care Nurse, Royal College of Nursing member, **Mr Martin Green**, Chief Executive, English Community Care Association, **Dr Jackie Morris**, Deputy Chair, Policy Committee, British Geriatrics Society, and **Ms Jo Peck**, Head of Nursing and Clinical Governance, Medicine Division, University Hospital Lewisham NHS Trust

Ev 47

Thursday 17 March 2005

Ms Trish Longdon, Deputy Ombudsman, and **Mr Colin Houghton**, Head of Continuing Care Team, Health Service Ombudsman for England

Ev 64

Dr Stephen Ladyman MP, Parliamentary Under-Secretary of State for Community Care, **Mrs Anne McDonald**, Head of Delivery Programme, Older People and Disability Division, and **Mr Craig Muir**, Deputy Director, Care Services Directorate, Department of Health

Ev 76

List of written evidence

Local Government Association and Association of Directors of Social Services (CC 30)	Ev 1
Age Concern (CC 29)	Ev 17
Alzheimer's Society (CC 26)	Ev 28
Citizens Advice (CC 15)	Ev 36
Royal College of Nursing (CC 21)	Ev 47
English Community Care Association (CC 4)	Ev 52
British Geriatrics Society (CC 19)	Ev 53
Office of Parliamentary and Health Service Ombudsman (CC 23)	Ev 64
Department of Health (CC 1, 9A)	Ev 76, 92
Paul Overton (CC 1)	
Progressive Supranuclear Palsy Association (CC 6)	
NHFA (CC 8)	
Enfield Disability Association (CC 10)	
Royal College of Physicians of Edinburgh (CC 11)	
Hampshire Social Services (CC 12)	
BUPA (CC 13)	
NHS Confederation (CC 14)	
Association for Children with Life-threatening or Terminal Conditions (CC 16)	
Solicitors for the Elderly (CC 17)	
Andrew Shaw (CC 18)	
Continence Foundation (CC 20)	
Motor Neurone Disease Association (CC 22)	
Office of Parliamentary and Health Service Ombudsman (CC 23A)	
Parkinson's Disease Society (CC 24)	
Relatives and Residents Association (CC 25)	
Help the Aged (CC 28)	
Help the Hospices (CC 31)	
Duncan Mackintosh (CC 32)	
Continuing Care Conference (CC 33)	
London Borough of Richmond Upon Thames (CC 34)	
The Law Society (CC 35)	
Marion Shoard (CC 36)	
Royal College of Physicians (CC 37)	
Commission for Social Care Inspection (CC 38)	

List of unprinted written evidence

Additional papers have been received from the following and have been reported to the House but to save printing costs they have not been printed and copies have been placed in the House of Commons library where they may be inspected by members. Other copies are in the Record Office, House of Lords and are available to the public for inspection. Requests for inspection should be addressed to the Record Office, House of Lords, London SW1. (Tel 020 7219 3074) hours of inspection are from 9:30am to 5:00pm on Mondays to Fridays.

Elizabeth Balsom (CC 2)

Gay Lee (CC 5)

Jane Williams (CC 7)

Pamela Coughlan (CC 27)

Ruth Hudsom (CC 39)

Fiona Burt (CC 40)

Reports from the Health Committee since 2001

The following reports have been produced by the Committee since the start of the 2001 Parliament. The reference number of the Government's response to the Report is printed in brackets after the HC printing number.

Session 2004-05

First Report	The Work of the Health Committee	HC 284
Second Report	The Prevention of Thromboembolism in Hospitalised Patients	HC 99
Third Report	HIV/AIDS and Sexual Health	HC 252
Fourth Report	The Influence of the Pharmaceutical Industry	HC 42
Fifth Report	The Use of New Medical Technologies within the NHS	HC 398-I

Session 2003-04

First Report	The Work of the Health Committee	HC 95
Second Report	Elder Abuse	HC 111 (Cm 6270)
Third Report	Obesity	HC 23 (Cm 6438)
Fourth Report	Palliative Care	HC 454 (Cm 6327)
Fifth Report	GP Out-of-Hours Services	HC 697 (Cm 6352)
Sixth Report	The Provision of Allergy Services	HC 696 (Cm 6433)

Session 2002-03

First Report	The Work of the Health Committee	HC 261
Second Report	Foundation Trusts	HC 395 (Cm 5876)
Third Report	Sexual Health	HC 69 (Cm 5959)
Fourth Report	Provision of Maternity Services	HC 464 (Cm 6140)
Fifth Report	The Control of Entry Regulations and Retail Pharmacy Services in the UK	HC 571 (Cm 5896)
Sixth Report	The Victoria Climbié Inquiry Report	HC 570 (Cm 5992)
Seventh Report	Patient and Public Involvement in the NHS	HC 697 (Cm 6005)
Eight Report	Inequalities in Access to Maternity Services	HC 696 (Cm 6140)
Ninth Report	Choice in Maternity Services	HC 796 (Cm 6140)

Session 2001-02

First Report	The Role of the Private Sector in the NHS	HC 308 (Cm 5567)
Second Report	National Institute for Clinical Excellence	HC 515 (Cm 5611)
Third Report	Delayed Discharges	HC 617 (Cm 5645)