



Response to
Health Select Committee Report
on Continuing Care

Presented to Parliament by
the Secretary of State for Health
by Command of Her Majesty
July 2005



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Response to Health Select Committee Report on Continuing Care

Introduction

This paper sets out the Government's response to the Health Select Committee's Sixth Report of Session 2004–05 on NHS continuing care.

The Government welcomes this opportunity to explore in detail several issues which were raised during the evidence sessions of the Committee. In particular, we welcome the opportunity to set out clearly the difference between fully funded NHS continuing care, and the registered nursing care contributions.

The Department has read and listened to all the evidence presented, and these views will inform the ongoing development of the national framework.

In addition, the Department's forthcoming White Paper will present a further opportunity to consider the future shape of the provision of care in primary settings informed by extensive public consultation.

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.

The Department is committed to involving service users and the people that support them, the NHS, local authorities, the voluntary and independent sector, and professional organisations in the continuing care national framework, and has been working with these key stakeholders already to inform the development of the framework. This dialogue will continue as the framework develops. We also agree that a formal consultation period in line with Cabinet Office recommendations should be part of the development of any written guidance.

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 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.

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.

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.

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.

The divide between health and social care provision, and the basis on which it is provided, has stood since 1948. To dismantle this would be a fundamental and costly change to the structure of the welfare state, which would go well beyond the scope of this inquiry. If by recommending that the Government remove the distinction between health and social care, the Committee is really recommending the removal of means testing for care services, then this would have significant cost implications. Considering long-term care alone, this would cost an additional £1.5 billion per year to provide free personal care. This cost is estimated to rise to over £3 billion, at today's prices, by 2020 and these calculations do not include the cost of 'board and lodging' which of course NHS patients currently receive. To provide free board and lodging to over 336,000 people currently resident in care homes would cost many billions of pounds more again per year. Such an investment would not provide any new services, nor improve the quality of services, nor benefit the less well off, whose care is already provided free of charge. As the Government has made clear many times, it has decided that this is not the best use of these significant sums, which it believes are better spent improving the range and quality of service provision.

The Department of Health will continue to promote joint working which delivers care designed for an individual. The key to providing seamless, high-quality person-centred services is the close working and communication between health and social care workers. The new continuing care framework will be based on the good practice that exists in integrated services, pooled budgets and structured communications, without imposing unnecessary bureaucracy on professionals. Clarity and agreement at a national level will allow health and social care professionals to be clear about their roles and responsibilities within a consistent framework.

The new framework will sit alongside a broad range of measures introduced by the Government to improve the quality of care and create a fairer balance of funding between taxpayers and individuals for long-term care, and one which creates real choices. For those requiring residential care, for example, the deferred payment scheme has since 2001 further encouraged councils to extend the scheme which allows individuals to put a charge on their home, meaning that they do not have to sell their home in order to pay for residential care home fees.

New intermediate care investment enables individuals to regain and maintain their independence, and extra care housing offers independence and choice to individuals to own or rent self-contained flats yet also have access to 24-hour support, meals, domestic help, on-site leisure and recreation facilities. These developments have led to a pattern of provision of care that is more flexible and can better respond to the needs and wishes of patients and their families. A record number of people are now being supported to live independently in their own homes, and are also being offered a choice of care and support when they leave hospital. These all allow the individual to have more control and choice over their care.

The Government has also provided more support for carers through the National Carer's Strategy, and the Carers (Equal Opportunities) Act 2004 which places a new duty on councils to inform carers of their right to an assessment of their needs, and requires councils to consider whether the carer works or wishes to work, undertakes or wishes to undertake education, training or leisure activities. The Government has also introduced the Carers Grant, which provides local authorities with the means to provide respite breaks and services for carers in England, and we have also introduced a performance indicator which ensures that councils recognise that support for carers continues to be a priority for the Government. All these measures support individuals and their families to provide care in the environment of their choice.

A range of initiatives in health and social care are promoting early intervention, prevention and self-care services to slow down or halt the deterioration of an individual's health and putting an emphasis on improving health and maintaining independence. We want the national framework for continuing care to build on this to develop an assessment framework which is centred on the needs and choices of the service users and the people that support them.

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'.

Assessment involves gathering all the information about a person's need for care. Eligibility for continuing care is based on whether the person's primary need is for healthcare. This decision is not based on where and how the care will be provided, which will be dependent on individual circumstances. People should not be denied fully funded continuing care at home *because* the people providing the care are not registered nurses; it is the nature of the care which is crucial. Decisions on full funding should not be based on definitions of nursing.

Following the assessment and establishment of whether or not the person's need is predominantly for healthcare, the next step is to plan the provision of the care. If it is decided that the most suitable setting for a person (who is not eligible for full funding from the NHS) to receive their care is in a care home providing nursing care, the NHS will fund the care by a registered nurse as its contribution to the care package. In these circumstances, this NHS contribution is defined in section 49 of the Health and Social Care Act 2001 as the services of a registered nurse in providing, planning and supervising a person's care, but it does not include any services which, due to their nature and the circumstances in which they are provided, do not need to be provided by a registered nurse. When care is provided in a care home (not providing nursing care) or in a person's own home, if care is needed from a registered nurse this is also provided free of charge, generally by the community nursing service.

In October 2001, we delivered on our commitment, set out in the NHS Plan, to remove the anomaly that residents of care homes providing nursing care were the only group of people who were means-tested for the services of a registered nurse. We did this by ensuring that the NHS meets the costs of care from a registered nurse in these care homes, as in all other settings. The NHS's contribution (the Registered Nursing Care Contribution) to a package of care which can otherwise be provided by a local council is based on the individual's requirement for care from a registered nurse. The local council's responsibility includes personal care, which is the term used to describe the help someone needs in order to carry out personal activities such as bathing, dressing and undressing, eating, and using the toilet. It may also cover advice, encouragement and supervision in these activities.

Local councils are responsible for commissioning social care services for their local communities according to local need, and Primary Care Trusts (PCTs) are responsible for commissioning health services for their local communities according to local need. The Health Act 1999 made it possible for local councils and the local NHS to pool their resources to get the most out of their budgets on behalf of their local population, and also broke down barriers to increase flexibility in the provision of services. In many areas this type of care is provided following the single assessment process and commissioned via a partnership arrangement. Partnership and integration are high on the Government's agenda and this is an example of the joint responsibility taken by the NHS and social services for an individual's care.

A key aim must always be that people receive good quality care appropriate to their needs, however it is provided or financed. The new national framework must ensure that all decisions are based on good assessment leading to a suitable level of care.

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 focused in depth on this issue during the 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.

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.

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 ensure security and dignity for people who need long term care, and which promotes their independence.

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.

The Government is committed to promoting the integration of health and social care at a local level so that older people and those with long-term conditions can retain their independence. The National Assistance Act 1948 sets out the framework within which local authorities decide what people can afford to contribute to social care costs. Capital assets and income have always been taken into account in making this assessment. Currently this means:

- For approximately 20,000 English residents, whose primary need is healthcare, all care and accommodation, when provided, is free. In previous decades this type of care was provided in the less homely environment of a long-stay hospital.
- Care from a registered nurse in a care home providing nursing care is funded by the NHS at between £129 and £40 per week, depending on need.
- A person with capital over £20,500 has to pay the full cost of their personal care and board and lodging – otherwise, councils assess a contribution based on a person's capital and income. No account is taken of capital below £12,500.

The Government does not believe that making personal care free for everyone is the best use of limited resources. Making personal care free for everyone would cost an estimated £8.4 billion over the lifetime of this Parliament (assumed to be 2005–08). This would consume most of the additional resources we are making available for older and disabled people. Furthermore:

- It would not help the poorest people, or the sickest, as the care of these people is already funded.
- It would divert resources from schemes that help all older and disabled people.
- It would, in particular, divert money that we use to help people maintain their independence and stay longer in their own homes.

We believe our alternative ten-point programme of measures, set out between 2001 and 2002, to improve standards of care and ensure fair access to services will generate more important benefits for all older people:

- Free nursing care in all settings including individual's own homes achieved in October 2001, paid for by the NHS;
- Intermediate care services for more than 300,000 people a year;

- A twelve-week disregard of property from the means test for residential accommodation following a permanent move into a care home, benefiting around 30,000 people a year plus the deferred payments scheme, whereby people can delay selling their homes in order to meet care costs. This gives people the option of not selling their home if they enter a care home. Councils have been given a grant to help them introduce this scheme;
- Free community equipment and intermediate care services from social services;
- The annual £185 million Carers Grant to fund short breaks for carers;
- Uprating, in line with inflation each year, the capital limits below which individuals will receive financial assistance to pay towards their care;
- Implementation of *Fair Access to Care Guidance*, so that everyone has equal access to care services based on an evaluation of their immediate needs and the likelihood that their condition will deteriorate;
- Availability of a direct payment from social services since 2000 to almost everyone who wants one and can manage it, to purchase care that best suits their needs;
- Rapid assessments for social care services, beginning within 48 hours and will be completed within four weeks. Following assessment, the services people need will be in place within four weeks; and
- £70 million, available by 2006, to support training for social care staff.

These benefits are not available to people in other parts of the UK that provide personal care free of charge. The allowance for free personal care in Scotland is £145 a week for those aged 65 and over living in care homes, but they do not receive attendance allowance (up to £60.60 a week), which is available elsewhere in the UK.

We will consider the recommendations of the Kings Fund study on the funding of social care for older people in England when it reports in the spring of 2006, but, on the subject of resources used in disputes between health and social care, the national framework aims to reduce disputes in two ways: first, by drawing up a framework which will provide clarity for patients and practitioners, so that there is less area for dispute; and second, by providing guidance in the shorter term on good practice for reviews and dispute procedures, which will reduce the time spent on disputes if they are inevitable.

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 country 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.

Although a single set of eligibility criteria will be one element of delivering coherence and equity, national criteria alone will not provide the answer. Indeed the independent review of nine Strategic Health Authorities (SHAs) in early 2004 identified several issues which also need to be addressed, including geographical variations in access due to a lack of awareness by professionals, and variation in application of the criteria caused by inconsistencies of approach by professionals. The new national framework, therefore, will set out national eligibility criteria, which will be drafted to ensure that all of a patient's needs are considered, including psychological and mental health needs. This is to ensure that the needs of people with, for example, dementia are considered on the same basis as physical needs. However, the framework will also include awareness-raising with professionals, clear communication with patients and their families, better and consistent training for professionals, and a consistent approach to continuing care assessments to ensure that the same information on needs is gathered for each person and tested against the criteria in the same way.

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.

At the time of the February 2003 Ombudsman's Report, national criteria would have involved consolidating over 95 different sets of former Health Authority criteria to one national set. This would have caused a great deal of turbulence in local provision. Second, the resources entailed in shifting to national criteria would have jeopardised the NHS's ability to respond to the Department's decision to adopt an extensive retrospective review and restitution process for individuals – which was the key part of the Ombudsman's recommendations.

In fact, the Department began action well before the 2003 Ombudsman's Report. The previous year, in August 2002, we asked the newly formed Strategic Health Authorities to align the sets of criteria from the previous Health Authorities into a single set for their areas and to ensure that these eligibility criteria were formulated in the light of legal advice. Now that 95 sets of criteria have been reduced to a broadly comparable set of 28, and as the retrospective restitution process is drawing to a close, it is appropriate and manageable to move towards national criteria, drawing on the lessons learnt by SHAs, and keeping up the momentum of increased awareness of continuing care that has been generated over the past few years. This was also the conclusion of the evidence presented in the Department's independent review of continuing care in 2004, *Continuing Health Care: Review, revision and restitution*. The framework will now be developed as a priority for the new Government.

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.

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.

Eligibility for continuing care must always be on the basis of need, not diagnosis. Our engagement with stakeholders to date has revealed that there is a general consensus that the national eligibility criteria can be designed to cover all client groups, including older people with mental health needs, younger adults with physical or mental health needs, and those with learning disability. We are clear that much of the disadvantage for younger adults or those with mental health needs is due to inconsistent assessment of needs against criteria and inconsistent awareness of continuing care among the health and social care professionals who work with these groups. This is precisely the issue the national framework will address with:

- national criteria;
- consistency of approach and assessment; and
- awareness supported by consistent training.

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.

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.

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.

Only once an assessment has established that a person is not eligible for continuing health care, should other packages of support by health and social services be considered – whether in the individual's own home or in a care home. If the individual needs to be in a care home which provides nursing care, then the NHS will need to decide its contribution to their care by determining the individual's level of need for a registered nurse. The national framework will make this relationship and process very clear.

In the 1970s most nursing care for people with higher levels of need was provided in NHS geriatric and mental illness hospitals. There was a professional consensus that these people's needs could be better provided for outside a hospital environment. The 1993 community care reforms introduced an assessment of need as the means of accessing suitable care outside of hospital. Following the Royal Commission on Long Term Care, a discrepancy became clear. Nursing home residents, (other than those entitled to full funding of their care and accommodation by the NHS) were being charged on a means-tested basis for receiving the services of a registered nurse. Anyone else who received these services in other settings (hospital, their own home or a residential home) received this care from the NHS free of charge. The purpose of section 49 of the Health and Social Care Act 2001 was to make clear that nursing care by a registered nurse was the responsibility of the NHS in any setting, including care homes providing nursing care. The policy of 'NHS funded nursing care' was introduced to correct the anomaly and implement section 49 of the 2001 Act.

The Registered Nursing Care Contribution (RNCC) is a means of determining the NHS's contribution to a joint package of care, where it is already clear that the NHS is not fully responsible for the care, but the services of a registered nurse are required. To correct the anomaly if someone requires the services of a registered nurse in a care home, the NHS will provide a proportion of the fees. The amount paid is based on the assessment of the level of need for care from a registered nurse, ie. 'high', 'medium' or 'low' banding.

Training in how to determine the need for care from a registered nurse (the Registered Nursing Care Contribution or RNCC) was rolled out through a training programme in September 2001. At that time it was made clear that this 'determination' was only relevant for care home residents receiving nursing care, but who had already been assessed as not meeting criteria for fully funded NHS care.

At the time that RNCC was introduced in October 2001 there were approximately 42,000 care home residents receiving nursing care who were funding their own care. These may or may not have had an assessment for fully funded NHS care in the past, but the training made it clear that the RNCC determination should not be carried out until eligibility for fully funded care had been considered and there was agreement that the individual was not entitled to fully funded NHS care. In April 2003 a further 90,000 residents of care homes providing nursing care, whose admission to the care home had previously been arranged following an assessment of their needs by social services, were assessed in a similar way.

Changing needs are monitored to ensure that the care provided still meets people's requirements. All residents should receive regular reviews (three months after first entry to the home and then at least annually), and additional reviews if circumstances change, including reviews on request from either the home or the individual/family.

Following implementation of the 2001 and 2003 guidance, the independent review of nine SHAs in early 2004 revealed evidence of a lack of understanding about the need for a decision on full funding by the NHS to be taken before any consideration is made about the level of input from a registered nurse that may be necessary. As a result, when the Minister, Stephen Ladyman, announced the work to develop a national framework for NHS continuing care he made it clear that this framework should also consider links to NHS-funded nursing care.

The development of the Single Assessment Process (SAP), has already been identified as the way to make sure that the process of assessment is handled correctly, consistently and proportionately. The SAP therefore applies equally to continuing care and RNCC assessments.

The national framework will be an opportunity to tackle implementation issues that surround continuing care and RNCC assessments.

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 into 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 these 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.

SHAs are currently responsible for formulating continuing care criteria for their area, which they have done in light of local legal advice and against the framework of guidance and directions issued by the Secretary of State. The Secretary of State has always believed, and continues to believe, that those whose primary need is a health need should be the responsibility of the NHS, and has reminded the NHS that continuing care criteria, or the way in which they are applied, ought not to place inappropriate responsibilities on local councils. In particular, the Secretary of State has made it clear that NHS-funded nursing care should only be considered once a person's eligibility for continuing NHS healthcare has been considered and that pathway has been ruled out.

The national framework will similarly be based on the findings of the Coughlan judgment, in so far as local authorities will not be expected to provide services beyond those that they can provide under section 21 of the National Assistance Act.

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.

The Access and Systems Grant for 2003/04 made money available to councils for new staff to carry out assessments for older people, and to help meet the new targets on assessment times announced in the 2002 Spending Review. This formed part of the £1 billion package of investment in older people's services announced by the Secretary of State on 23 July 2002.

The Access and Systems Grant for 2004/05 and 2005/06 is a grant without specific conditions and in both years the grant has been increased by an additional £100 million for older people's services. The grant guidance describes its intended purpose, which include resources to support the implementation of SAP.

Through the National Programme for IT, resources are also being made available for the NHS Care Records Service, which will need to support both the NHS and social care. In many respects, however, the guidance on SAP simply formalises good assessment practice and care planning, which to a large extent should already be everyday practice.

In order to ensure that the implementation of SAP is effective, we are establishing an electronic social care record (ESCR) implementation board to take forward policy in relation to the ESCR and SAP. Acknowledging that the progress of implementation of SAP has not been uniform, the Department has established a separate and specific strand of work to champion SAP across other government departments, within the Department of Health and at a national and a local level. This work will tie closely to the implementation of the green paper *Independence, Well-being and Choice* and subsequent work on the future of social care.

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 that 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 an assessment (or re-assessment) within a specified timescale.

The principles of SAP make clear that assessment should be proportionate to the presenting needs of the individual and conducted by the appropriate members of a multi-disciplinary team. Since the introduction of the Community Care (Delayed Discharges etc.) Act in 2003 the NHS has to proportionately assess a patient's needs for fully funded NHS continuing care against SHA eligibility criteria before an assessment notification for services from social services (section 2 notice) is issued. This requirement responded to comments in the Ombudsman's 2003 report on continuing care, and ensures that adults discharged from acute beds are automatically screened for continuing care. The national framework will examine the review process, and will establish and disseminate good practice on triggering reviews.

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 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.

As recognised in the independent review of continuing care in nine SHAs, tools should be approached with care, and should be viewed as providing consistency of approach and an aid to decision-making, rather than providing a definitive answer. As part of the national framework we are naturally considering the use of a national tool or a range of compatible national tools to structure the decision-making process. The Department is working towards furthering the sharing of good practice in order to make the decision-making process more consistent and transparent and the whole system easier to operate and understand. This will further reduce inconsistencies in eligibility across the country.

In line with *Independence, Well-being and Choice: Our vision for the future of social care for adults in England*, we will develop an approach to assessment that puts people using services and carers at the centre of needs assessments.

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.

One aspect of the national framework will be to provide information and guidance to promote a shared understanding and consensus among professionals on the subject of continuing care. When an assessment for continuing care is carried out it should involve professionals with the relevant experience, and where necessary the specialist knowledge, to ensure that all the needs of the patient have been duly taken into account. The professionals involved should depend on the presenting needs of the patient. It is not appropriate to be more prescriptive, as the presenting needs of one patient will be very different from another and will require a different set of professionals to be involved in their care and assessment. The implementation stage of the framework will ensure that health and social care professionals are aware of the revised assessment framework, and know where they can find means for support, explanation and further training.

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 those to be carried out flexibly and promptly.

Regular reviews of eligibility are important to ensure that an individual receives the right care at the right time in the right place, as is stated in the 2001 guidance on continuing care (HSC 2001/015). HSC 2001/17 (Guidance on free nursing care in nursing homes) goes on to say that everyone entering a care home on a permanent basis after 1 October 2001 should have their registered nursing care needs reviewed after three months, and then every 12 months thereafter or when there is a significant change in their health needs. Requests for review should be made via the nursing home co-ordinator.

The national framework will raise awareness of this guidance, and share good practice around procedures for triggering reviews.

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.

The national framework aims to put the needs and wishes of service users and those who support them at the centre of the assessment process. It also aims to improve the information available to service users and those who support them, and to encourage a better dialogue and improved information-sharing between professionals and service users and the people that care for them.

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.

The Department is working with SHAs to identify current audit practices at SHA level, and using this collaborative work to establish a national system of auditing and benchmarking consistency.

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 financial 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 decision being made by Directors of Finance.

PCTs which do have a panel to collate the eligibility assessments from the various health and social care professionals, should never act as a financial gatekeeper, and it is inappropriate for such panels to have a Director of Finance sitting on the panel. The national framework will examine the role of these panels where they do exist, as part of the work on the assessment process.

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.

It is important that all retrospective review cases are investigated thoroughly and accurately, as the Department is committed to reviewing each application on its own merits. The Department issued an outline of a suggested procedure which might be followed by SHAs/PCTs in developing their process for retrospective restitution. The Department's independent review found that all nine SHAs surveyed drew on this outline procedure, and the NHS Confederation has reported that its members found the Department's guidance helpful for providing a framework. Contact was maintained with the SHA Older People's leads throughout the review process.

The process of undertaking an in-depth review involves contact with many health and social care organisations and bodies, and as such there have been considerable delays in obtaining all the relevant records and patient data. In some cases data and information from older cases has been lost and it must, where possible, be gathered from alternative sources, which is unfortunately a lengthy process.

The number of requests for retrospective reviews was large, generated mainly by the publicity surrounding the Ombudsman's report. However, more than 10,750 cases have now been reviewed. Apart from in exceptional circumstances, SHAs are striving to complete all new cases coming to light within two months of the receipt of all the relevant documents. Processes have been adapted to take account of recommendations from the Ombudsman's office, and emerging good practice; and lessons learnt from the review process nationally, and at SHA and PCT level, will inform any future reviews, and indeed the national framework itself.

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 or mouth to encourage claimants to come forward. We would urge the Government to endeavour to continue to identify people who might have been affected.

All living individuals in receipt of services will be subject to regular reviews and so should have their case looked at again since the beginning of the restitution process.

The template issued by the Department called for SHAs to identify cases since 1996, and all SHAs have followed this advice. All SHAs undertook advertising and publicity in order to raise awareness of the restitution process. Local publicity by SHAs has brought restitution to the attention of a significant proportion of self-funders or their families.

The cost to the public of investigating non-referred cases, where the recipient is deceased, far outweighs the slight possibility of a small amount of recompense being owed to the next of kin of a very small number of deceased individuals, even assuming that the next of kin and their records are traceable.

The action taken by the NHS in the use of its resources must be proportionate. The Department has asked SHAs to satisfy themselves that they have taken relevant steps to ensure that everyone is aware of the review process.

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.

It is regrettable that in the past record-keeping was of variable and at times dubious quality. However, steps have been taken to remedy this.

The Care Homes Regulations issued in 2001 explain in detail what records care homes should keep, and they stipulate that these records should be kept for a minimum of three years after the last entry. Since the introduction of the Community Care (Delayed Discharges etc) Act 2003, the decision to refuse or assess for continuing care should be recorded in the patient's NHS records, and the retrospective review process has highlighted among assessors the need for such notes to be legible and comprehensible.

The introduction of SAP ensures high-quality record-keeping. The Department also confirms that SHAs have been given specific instruction to consider all relevant and available evidence for the purpose of retrospective reviews, especially in cases where original records are unavailable.

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.

The Department is working with the Ombudsman's office on this issue.

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.

If an individual's needs are assessed as meeting the eligibility criteria then they will receive continuing care. Subject to clinical safety and the need to balance competing demands on the NHS to provide a comprehensive health service to other service users, continuing care can be provided in any setting including an individual's own home. The Department believes that funding systems already recognise that an institutional setting is not the only or necessarily always the best place for these needs to be met.

In the light of the consultation on the Green Paper on adult social care, the Department will consider ways of increasing flexibility for individuals whose needs move from being the responsibility of social services to the responsibility of the NHS, to enable greater consistency for service users and the people that support them.

In the case of the work associated with the Green Paper, the Department is working with other government departments to pilot and evaluate the use of individual budgets for adults with a disability or with an assessed need for social care support. This approach entails allocating available resources in the form of individual budgets which would provide people with choice, empowerment, freedom and clarity about how the resources were used. However, as the local authority would be responsible for the budget, the individual would not have to worry about actually managing the money for themselves.

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 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.

The introduction of RNCC brought the issue of offering incentives for high-quality care to the attention of the NHS: HSC 2003/006:LAC (2003)7 (Guidance on NHS funded nursing care) states that:

PCTs and councils, as commissioners of services (Guidance on NHS funded nursing care) should consider ways in which they can identify and reward good performance by providers of care, particularly for those that have a proven record in the rehabilitation/re-enablement of residents in their care.

The Department recognises that supervision and management of care is an essential function in ensuring that individuals maintain their optimum potential, and constitutes an integral part of their care. This approach is also in line with the Government’s policy of maintaining independence.

This issue will be made more explicit in the review when looking at the interface between RNCC and continuing care as part of the national framework. Other initiatives, such as the long term conditions framework and *Independence, Well-being and Choice*, the Government’s Green Paper on adult social care, also recognise that improvement, prevention of deterioration and maintenance of good health are important responsibilities for the NHS and social care providers.

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.

When this issue came to the attention of the Department, Health Minister Jacqui Smith announced a package of measures to stop some care home providers taking advantage of the Government’s NHS funded nursing care initiative to artificially raise fees for residents.

The package included three key measures:

- amendments to regulation 5 of the care home regulations to oblige homes to provide a breakdown of their fees. This makes it clear to residents which aspect of their fees relate to nursing care and which to residential care. It is an offence to withhold a breakdown of fees and it may be possible to cancel the care home's registration if this situation occurs;
- a central core contract that NHS bodies should use as a basis for spelling out how any NHS nursing contribution received by care homes is accounted for by them; and
- a request to the Chair of the National Care Standards Commission (whose functions have now transferred to the Commission for Social Care Inspection) that standard 2 of the National Minimum Standards for Care Homes for Older People be enforced more rigorously. The standard states that any contribution to fees by the NHS or a local authority is to be recorded separately from other contributions from the service user, a relative or other third party.

The Department will remind the Commission for Social Care Inspection of the importance of enforcing inspection against standard 2 of the National Minimum Standards for Care Homes for Older People.

The measures that the Department has taken ensure that residents and their families receive comprehensive information about what their fees are paying for. Although we have not yet published our response to the Office of Fair Trading's report *Care homes for older people in the UK* our initial response is that we fully support the Office of Fair Trading when it reminds care homes that contracts with the public should be both clear and fair.

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.

If a person is assessed as being eligible for continuing care, then those assessed needs will be met. Subject to clinical safety and the obligations of the NHS to provide a comprehensive health service to other service users, continuing care can be provided in any setting including an individual's own home. However, the way that the service is provided should not use resources to a disproportionate extent. As a matter of good practice, when a care home resident's needs worsen so that they become eligible for continuing care the risks (both physical and emotional) of moving that resident should be fully considered before a decision is made to move him/her. However, the Department cannot say that continuing care should always be provided in the care home where an individual is currently resident, since this would constrain the NHS's responsibility to provide appropriate care (the care home may not be able to provide the type of care needed) and manage its finances.

As previously stated, a review can be requested at any point when someone believes that their condition has changed: this person may be a carer, a relative, a health or social care professional, or the patient themselves.

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.

The national framework for continuing care will aim to include national criteria which take account of psychological and mental health needs as well as physical, and which are Coughlan-compliant and based on current legal requirements. The framework will also address the implementation issues that have arisen in recent years around the interaction between RNCCs and continuing care, and will examine measures which reward high-quality care, and encourage flexible approaches to care provision based on the choices, rights and preferences of the service user. The framework will aim to improve the consistency of application of the criteria, by delivering a range of compatible national determination tools to aid in the decision-making process, and will look at measures to disseminate learning.



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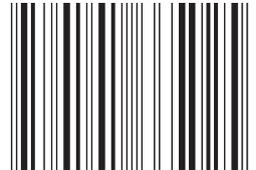
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