



***Charging for the privilege of being ill?
Problems and opportunities
with long term care***

Charging for the privilege of being ill? Problems and opportunities with long term care: A view from the RCN

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Executive Summary

Long term care for older people is an area of recurrent and unresolved difficulty. Recent debate has been characterised by disputes over who should pay for care and whether some people have been unfairly (and illegally) charged for care which should have been provided free of charge by the NHS. These are important questions. There are also equally vital issues about the nature and quality of long term care - and *that* debate has scarcely begun.

The Royal College of Nursing (RCN) commissioned independent consultants Melanie Henwood and Eileen Waddington to undertake a short term research project to explore the perceptions and experiences of RCN members about continuing health care for older people. This is the report of that research. It provides insight to the informed and expert views of nurses on these issues, and should better enable the Royal College of Nursing (RCN) to contribute to the emerging national debate.

Policy development and debate

Disagreement over the respective responsibilities of the NHS and social services for long term care is nothing new, and reflects the blurring of boundaries between the two services. In recent years, however, the dispute has intensified, and many commentators argue that this is indicative of the NHS's retreat from the area of long term care and the transfer of responsibilities to social services - and thereby to patients and their families.

Section 1 of this report reviews the policy development and debate, particularly that since the introduction of the community care reforms following the NHS and Community Care Act, 1990. It traces the emergence of eligibility criteria for NHS continuing health care in 1995, and the on-going legal disputes (notably the Coughlan judgment in 1999) that have accompanied implementation.

The 1999 report of the Royal Commission on Long Term Care offered a possible solution to the difficulties with long term care; it recommended that *all* personal care should be free. This, it was argued, would remove the artificial separation of health and social care. The Government did not accept this recommendation, which it regarded as unaffordable (although the recommendation was implemented by the Scottish Parliament). A compromise led to the introduction of new arrangements to contribute to the costs of registered nursing care, known as the Registered Nursing Care Contribution or RNCC. This brought a new critical interface between RNCC and fully funded care, which has proved to be highly significant.

The NHS Ombudsman has become increasingly involved in investigating complaints about long term care, and in 2003 the NHS funding for Long Term Care report accused the Government of failing to ensure a fair, transparent and country-wide system for funding long term care so that hardship and injustice for many patients and families developed. The Government responded by requiring strategic health authorities to undertake a retrospective review of patients who may have been wrongly denied continuing care, and to make refunds of costs where this was proven. Some 12,000 cases have received full or partial restitution at a total cost of £180 million.

In December 2004, the Minister of State for health told the House of Commons that a new national framework for continuing care would be developed in order to improve consistency around the country. This work is on-going. The House of Commons Health Committee undertook a short inquiry into continuing care, reporting in April 2005. The RCN submitted evidence to the inquiry and many of the recommendations that were subsequently made by

the Committee have been echoed, and indeed amplified, by the current research with RCN members.

Problems and opportunities

Section 2 of this report explores the problems and challenges in continuing care identified by RCN research participants. In examining these criticisms, it is important to understand that many respondents set their comments in a clear moral framework and a fundamental belief that the NHS should be fair to all patients.

On trying to establish an equitable system, participants widely agreed that the way forward must lie in the development of *national* eligibility criteria for continuing health care. These would replace the current 'postcode lottery' where different criteria are operated in each of the 28 strategic health authorities.

RCN members viewed merely integrating disparate criteria into a single statement of eligibility as insufficient. Respondents highlighted the need for a fundamental revision of the basis of criteria, and for ensuring that the approach and definition of criteria is both clear and sufficiently inclusive. At present, nurses are concerned that criteria overlook the needs of many people because of an inappropriate focus on physical needs alone, to the exclusion of psychological and mental health care needs.

The application of criteria raises a number of difficulties, and if greater consistency is to be achieved RCN respondents were strongly in favour of more coherent approaches to assessment. There is some enthusiasm for the use of tools or methodologies for assessment, but a reluctance to reduce everything to a 'tick box mentality' that does not allow for the vital contribution of professional and clinical judgment.

The lack of choice on offer to people with continuing care needs is a striking finding. Many people accept that choice *should* be supported, but in practice respondents described situations in which patient choice was compromised by financial imperatives and the operation (explicitly or by default) of cost ceilings on community-based packages of care.

The quality of care provided raises multiple issues: how care is commissioned, how this relates to the assessed needs of individuals, and how provision is monitored and audited. The debate about long term care has clearly been overly concerned with defending eligibility, rather than addressing what happens to people once they enter the care system. RCN respondents showed deep concern about the lack of attention paid to many of the most frail and vulnerable members of society.

The introduction of the Registered Nursing Care Contribution (RNCC) proved to be a watershed in the development of continuing health care. RCN participants identified the enormous practical difficulties in distinguishing between RNCC and fully funded NHS continuing care, and the poor consequences this can have for patients. They raised particular concerns about the apparently perverse incentives which are institutionalised by the RNCC. For example, dependency of patients attracts greater funding yet best practice in nursing requires a re-enablement approach. However if this is successful and the patient improves as a result, then the funding is reduced despite the fact that greater nursing time and skills are required for rehabilitation. The banding system does not respond flexibly to the needs of patients, nor does it reflect best practice in nursing. Operating two parallel systems is not only confusing, but is also highly costly and bureaucratic.

Many RCN members participating in this research were involved in the retrospective review and restitution process. Their experiences had been difficult, and the demands of trying to undertake individual reviews with inadequate case notes and information, alongside their

other commitments, were widely remarked on. Members had concerns that the retrospective review process had raised expectations that it was unable to meet and caused stress for patients and their families. However, for those patients who were granted financial restitution as a result, there were clear benefits. It was also clear that the audit of past decisions provided by the review drew attention to some very poor quality practices (not least in assessments and the standard of record keeping), and has highlighted the need for nursing staff to raise their future performance and competence.

Conclusions and ways forward

The problems with long term care that were identified by the research led us to draw some clear conclusions and indications of how the RCN should take the debate forwards. RCN respondents demonstrated clear support for the development of a national approach to continuing health care that would also address the relationship with RNCC. Respondents also showed considerable consensus on the need for technical support for implementation of a new approach through development of appropriate assessment tools.

Training and awareness-raising clearly have a major contribution to make in developing the necessary skills throughout the NHS. Too often specialist nurses feel they are let down by the poor understanding and knowledge of their colleagues in the acute health sector, where there is little appreciation of the issues around continuing health care and poor awareness of the triggers for identifying potential cases.

Improving assessment skills will also necessitate a shift in the culture of the NHS in general, and of the world of nursing in particular. Assessment has to be approached in a far more person-centred manner than is often the case, and seen as a key tool in promoting choice and control for older people. These values need to be incorporated in a much more focused approach to care planning and review. Care plans should reflect the assessed needs of individuals in a much more dynamic way, providing the basis for arranging, delivering and monitoring care. These are the necessary means to achieve person-centred care for the most dependent and frail members of society.

There is a significant challenge for nurses to reclaim the value of their role and their contribution to care. Many participants were concerned by the apparent lurch of nursing towards a highly technical model which celebrates advanced practitioners, while paying insufficient attention to fundamental caring values and activities.

The findings from the research with RCN contributors are in many ways consistent with other recent work. However, there is also a distinctive element provided by the unique nursing perspective, grounded in every day practice.

There are many concerns around continuing health care, but RCN participants also recognised that there are opportunities to tackle these. There is now potential to move past the often sterile debates about the long-standing problems with continuing care, and to focus instead on moving towards a new model based on principles of fairness and equity, and seeking to deliver a consistent, individualised, high quality and flexible model of care, fit for the twenty-first century.

Section 1: Introduction

- 1.1 The Royal College of Nursing commissioned independent consultants Melanie Henwood and Eileen Waddington to undertake a short term research project to explore the perceptions and experiences of RCN members about continuing health care for older people. The work was undertaken between February and April 2005. The approach and methodology of the project are summarised later in this report. We begin by setting the research in the context of recent policy development and debate.

Policy development and debate

- 1.2 The respective responsibilities of the NHS and local authority social services for long term care have long been the focus of confusion, uncertainty and controversy. In part, this is indicative of the wider difficulties that arise at the interface of the two services. Since the establishment of the welfare state in 1948 there have been parallel and, at times, overlapping responsibilities. The National Assistance Act of 1948 placed a duty on local authorities to provide residential accommodation “for persons who, by reason of age, infirmity or any other circumstances are in need of care and attention not otherwise available to them”. At the same time the National Health Service also had responsibilities for long term care hospital provision. This separation was re-iterated in the 1989 White Paper *Caring for People* that laid the foundation for the NHS and Community Care Act of 1990, which still provides the broad framework for community care policy. It was stated that while the main responsibility for community care would reside with the local authority:

“..there will be others, in particular elderly and seriously mentally ill people and some people with serious mental handicaps together with other illnesses or disabilities, whose combination of health and social care needs is best met by care in a hospital setting. There will be a continuing need for this form of care.”¹

- 1.3 The policy also emphasised that there was an ongoing responsibility for the NHS to provide for non-acute nursing needs, yet there was growing evidence that the health service was systematically disengaging from such services. In the lead up to the implementation of the 1990 Act in April 1993 there was considerable concern that the pace of NHS withdrawal from long term, or continuing health care, would accelerate.

1995 Guidance on NHS continuing care

- 1.4 The Department of Health issued guidance (England) in 1995 to confirm and clarify the responsibilities of the NHS. The guidance was issued in response to a number of concerns raised in a report by the Health Service Commissioner. The Commissioner had investigated the failure of Leeds Health Authority to make available long term care for a seriously incapacitated patient who no longer required acute health care, but did require full time nursing care².
- 1.5 The guidance stated that “the arrangement and funding of services to meet continuing physical and mental health care needs are an integral part of the responsibilities of the NHS”³. The guidance pointed out that these responsibilities

include, but are not limited to, arranging and funding an appropriate level of care from the NHS under specialist clinical supervision in hospital or in a nursing home. The responsibilities of the NHS for continuing health care were also stated to include “equally important responsibilities around rehabilitation, palliative health care, respite health care, community health services support and specialist health care support in different settings”. All health authorities (England) were required to review their arrangements and to develop policies and eligibility criteria for continuing health care.

1.6 The difficulties of disputed health and social care responsibilities for continuing health care did not end in 1995. A judgment issued by the Court of Appeal in 1999 (the Coughlan Report) explored responsibilities in terms of:

- whether the nursing services provided were incidental or ancillary to the provision of accommodation which a local authority is under a duty to provide
- whether the nursing services provided were of a nature such that it can be expected that an authority should provide them, given that its primary responsibility is to provide social services
- whether a local authority is excluded from providing nursing services where the NHS has in fact decided to provide them.

1.4 The Coughlan judgement prompted further guidance in 1999⁴ and in 2001⁵ which required health authorities to ensure that their policies and eligibility criteria were compliant with the judgment and existing guidance. Further change followed with the implementation of Section 49 of the Health and Social Care Act, which removed from councils the responsibility for providing nursing care by a registered nurse. This was paralleled in October 2001 by the implementation of NHS funded nursing care (the Registered Nursing Care Contribution – RNCC), which made the NHS responsible for funding care in nursing homes provided or supervised by a registered nurse.

NHS funded registered nursing care

1.5 The introduction of NHS funded nursing care flowed from the publication of *The NHS Plan* in July 2000⁶. This provided the Government’s response to the report of the Royal Commission on Long Term Care published in 1999⁷ which had recommended that all personal care should be free of charge. The Government rejected this recommendation as unaffordable, but *The NHS Plan* accepted that registered nursing care *should* be free of charge to the recipient in all settings. This recognised the anomaly that had gradually developed between people in nursing homes, some of whom were responsible for some or all of the costs of their nursing care, and those receiving registered nursing care in hospital or in the community, who were not responsible for the costs. *The NHS Plan* announced that the health service would therefore meet the costs of registered nurse time spent on providing, delegating or supervising care in any setting. Section 49 of the Health and Social Care Act 2001 removed local authorities’ responsibilities for providing nursing care, which was defined in these terms:

“services provided by a registered nurse and involving either the provision of care or the planning, supervision or delegation of the provision of care, other than any services which having regard to their nature and the circumstances in which they are provided, do not need to be provided by a registered nurse.”

- 1.6 The Government emphasised that the new requirement to fund the registered nursing care of people in care homes would not reduce the responsibilities of the health service to arrange continuing NHS health care. A three banded approach was adopted for determining registered nursing care: low, medium and high. Determining which category a patient requires is made using a framework of stability, predictability, risk and complexity⁸. Clearly, the interface between RNCC determination and assessment for NHS continuing health care is a critical one.

The involvement of the NHS Ombudsman

- 1.7 The NHS Ombudsman issued a report in February 2003 that highlighted investigations into four complaints about NHS funding for long term care. The cases featured shortcomings in eligibility criteria that were highly restrictive or failed to comply with guidance, or with the Coughlan Court of Appeal ruling. The Ombudsman was highly critical of the Department of Health and argued that guidance and support had failed to ensure that a fair and transparent system of eligibility for funding for long term care could operate throughout England. Guidance had frequently been misinterpreted or misapplied by health authorities, resulting in hardship and injustice for patients and their families⁹. Following the Ombudsman's report, the Department of Health required all strategic health authorities (SHAs) to complete work with local councils in developing one set of criteria for continuing health care in each SHA (as had been required in the 2001 guidance).
- 1.8 The Department further required that SHAs should review whether continuing care criteria in use in their area since 1996 were consistent with the Coughlan judgment, and to investigate cases where people may have been wrongly denied continuing care, either because the criteria were wrong or they had been incorrectly applied in individual circumstances. Where investigation found such cases to be valid, appropriate financial recompense was to be made to the patients concerned or to their estates. Investigations were to be completed by the end of December 2003; this deadline was subsequently extended to 31 March 2004. In total some 12,000 cases were reviewed and full or partial restitution was awarded in around 20% of cases at an estimated cost of £180 million.
- 1.9 On 9 December 2004, a written statement was issued by the Minister Dr Stephen Ladyman. He announced the publication of an independent review of continuing care¹⁰ which had informed a decision to "move to a national framework for local implementation." The Minister welcomed the work that had taken place in SHAs in conducting the reviews and restitution, and in revising eligibility criteria which were all now judged to be "fair and legal." Building on this, a national approach would be developed in order to improve consistency and ease of understanding for practitioners and patients alike¹¹.

Inquiry by the Health Select Committee

- 1.10 In response to the statement from Dr Ladyman, the House of Commons Health Committee announced on 21 January 2005 that it would undertake a brief inquiry 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 report

of the inquiry was published on 10 April 2005,¹² and made a number of recommendations, including the following:

- removal of the structural division between health and social care
- establishment of a single set of legally compliant national eligibility criteria for continuing care which take equal account of psychological and mental health needs as of physical care needs
- integration of two parallel systems for funding continuing care and registered nursing care
- establishment of a national standard assessment methodology, supported by a national training programme, to ensure assessments against national criteria are carried out robustly and uniformly
- redesign of the system for funding continuing care and nursing care to reward high quality care and promote rehabilitation and independence rather than rewarding dependency
- introduction of greater flexibility in funding NHS continuing care to enable people to be cared for more easily in their own homes, if that is their preference.

1.11 Many of the themes and issues identified by the Health Committee have strong resonance with the findings from the research with RCN members.

1.12 This brief overview of the chronology of national policy development sets the scene for the work undertaken for the RCN. The problems of inconsistency and inequity in continuing health care are long standing, but the latest policy announcements signal a change of gear. It is against this context that the RCN commissioned a modest investigation to explore members' perceptions and experiences of continuing health care and NHS funded nursing care.

RCN report: aims, objectives and methodology

1.13 The project provided a snapshot of RCN member perspectives on continuing health care and NHS funded nursing care for older people. It explored nurses' views on:

- the key issues that need to be addressed in developing a new national framework for continuing health care
- principles of equity and fairness in continuing health care
- the quality of care that is and should be provided
- experiences of the review and restitution process
- the distinctive contribution of nursing to long term care.

1.14 The research took place in three inter-linked phases. The first featured a specially developed on-line questionnaire administered through the RCN website, and completed by 66 respondents. The second phase involved qualitative research structured around five focus groups of RCN members held in a range of locations around the country. In total, 34 people participated in these group discussions. The

focus groups were complemented by a series of semi-structured telephone interviews with ten key respondents who were randomly selected from a list of people who had indicated they would be willing to take part in the research. The third phase of the research was an analysis of all the material, and the production of this report.

1.15 Section 2 gives the key findings from the research. This is written in a cross-cutting, thematic style which integrates the material from all phases of the project.

Section 2: Problems and challenges in continuing care

- 2.1 The RCN members who participated in the research identified many problems with the current arrangements for NHS continuing care and funded nursing care. These perceptions of difficulties are grounded on nurses' wealth of day-to-day experience over many years. Participants' professional backgrounds were very varied, but most had direct experience of undertaking assessments for the registered nursing input (RNCC) and of continuing care practice issues (particularly as older people's nurses).

Fairness and equity

- 2.2 In all components of the research, but particularly in the qualitative phases, participants made frequent reference to a moral framework within which they operated. This was reflected in repeated comments about 'fairness' for people needing care from the NHS. Some nurses had their own convictions that "all personal care should be free," and referred to the policy direction that has been pursued in Scotland, where the full recommendations of the Royal Commission on Long Term Care have been implemented. However, the issues about fairness go much further than this argument.
- 2.3 It is important that the discussion about problems that follows is located within this context; continuing care is frequently experienced as problematic *precisely because* it offends against a sense of fairness and equity. Nurses described a prime motivation of "just trying to do our best for patients," and "if someone has care needs, that's all that matters", and "I will make sure that people get what they are entitled to." These comments show how nurses are often embattled in trying to get what they believe is right for their patients, and feeling that they have to fight their way through a system which appears to be geared towards denying people the care they need.
- 2.4 While there are issues of justice or fairness about continuing care for all groups, they are often pointed out about older people. It is these people who trusted in the promises of the welfare state and believed they would get the care they need. The fact that many find themselves excluded from fully funded continuing care, or that they receive poor quality assessments and care, is seen as a manifestation of the inherent ageism of society. This also means that many families who should be spending time with an elderly relative in their final days, dealing with what is "a painful journey" for them all, are instead too often caught up in disputes and arguments with health and social services and "battling for the basics." As another respondent remarked,
- "It's a very emotive situation – money and care – it hurts. People who have worked hard all their lives, and then they find they have to pay for care; it's a tinder box."*
- 2.5 Many of these issues surfaced with particular force during the process of retrospective review and restitution for NHS continuing care. We will return to this discussion later in the report.

Eligibility criteria for NHS continuing care

- 2.6 None of the respondents involved in the study believed that eligibility criteria for continuing health care were unproblematic. One respondent argued that the reason for this was clear: “the system is fundamentally flawed.” Issues that recurred included:
- difficulty of understanding the criteria and the meaning of particular terminology
 - criteria that exclude particular groups of patients or types of need.
 - continuing variation between SHAs and primary care trusts.
- 2.7 Respondents frequently observed that varying eligibility criteria led to “a postcode lottery” in access to care. Interestingly, this was also a central feature of evidence to the inquiry by the House of Commons Health Committee. The operation of 28 different sets of criteria by the SHAs was recognised as an improvement on the recent past, but still produced enormous variation and inequity between patients living in different areas. This also links in to the nurses' concerns about fairness. Without the same criteria operating nationally, it is difficult for a system to be perceived as ‘fair’, and:
- “the public needs to feel it is fair and equitable – not a postcode lottery.”*
- 2.8 There is a dilemma for the health service about the balance between centralised control and local autonomy. The approach of the Department of Health is one that is increasingly decentralised, and with primary care trusts (PCTs) responsible for more than 80% of all NHS resources it becomes very difficult to run things along the ‘one size fits all’ model of the past. Some respondents recognised this tension and acknowledged that there will always be *some* variation, because “you can’t have local autonomy and equity across the country”.
- 2.9 Numerous examples were cited of cases in which people moving into an area from another SHA would be found on assessment to fit the criteria for NHS continuing care, when they had not done so previously (or the reverse).

Terminology and definitions

- 2.10 The 1995 Department of Health guidance on continuing health care stated that eligibility for care should be determined by reference to:
- the complexity, intensity or unpredictability of care needs requiring the regular supervision of a consultant, specialist nurse or other NHS member of the multi-disciplinary care team
 - where a person routinely required the use of specialist health care equipment or treatment which needed the supervision of specialist NHS staff
 - where they had a rapidly degenerating or unstable condition, requiring specialist medical or nursing supervision

- where there was a prognosis that someone was likely to die in the very near future.

All these situations raise questions about definitions and what these terms actually mean in practice. A related difficulty is that criteria developed within this framework are often biased towards physical care needs and take insufficient account of psychological and mental health needs (for example, concerning people with dementia). The following observation makes the point:

“The decision about nursing input is a judgment about what nursing is. Some 70-80% of care home residents have dementia, but their mental health nursing needs are often not assessed, even where that input could make a difference. The definition of criteria around stability etc often doesn’t pick them up.”

- 2.11 As many respondents also pointed out, the needs of other client groups also suffer adversely from narrowly defined criteria. Members saw this as an issue in the care of children with continuing care needs, and younger adults with physical disabilities.

Application and interpretation

- 2.12 However clearly defined eligibility criteria are, respondents recognised that in practice much depends on how these are interpreted and applied in individual circumstances. There is enormous variation in how this happens, and which approach to assessment is followed.

- 2.13 An issue repeatedly identified was the lack of knowledge and understanding of continuing care of many key people in the health service. This is also exacerbated by the pressures on acute hospitals to accelerate patient transit, which can jeopardise timely assessments of need.

- 2.14 A basic understanding of the role of NHS continuing care is often absent. Respondents described situations in acute hospitals where staff were reluctant to identify possible eligibility for continuing care because of the extra time such assessment would require and the possible implications for delayed discharges. For example:

“The problem is, everything happens so quickly on the ward – moving people is a priority rather than assessing need.”

And:

“They want the bed now. People are treated like pieces of furniture (...) People don’t enable at the same speed – there are issues about opportunity and choice (...) I don’t know how people get assessed because they are never in one bed long enough.”

- 2.15 It was also reported, for example, that in some PCTs “if social services get a whiff of continuing health care they won’t touch it,” which again introduces potential delays to discharge from hospital which staff are keen to avoid. This is also indicative of the particular relationships between health and social services operating in local health economies. Where those relationships are poor, the prime concern is with protecting budgets rather than addressing person-centred care. As this respondent observed:

“There are different levels of politics in all of this; we have to make a needs assessment that is balance against financial imperatives, and there is no easy solution. You need to have very strong clinicians to advocate for the client.”

- 2.16 Many respondents emphasised that a needs-led approach should always be followed, and that “if someone meets the criteria, we should make the funding available”. However, members also recognised that this often did not happen, and decisions would instead be made on the basis of resource concerns and commissioning practices. This would lead to patients being told, for example, “we don’t have continuing care here,” or “provision gets interpreted according to PCT budgets – what they will and won’t fund; it’s not needs-led”. Other concerns were raised about assessment for people who are self-funding, where their needs for care get mixed up in funding issues, as this observation indicates:

“If someone had money, then people didn’t do an assessment so proactively. It is very clear that self-funders are told to go and find a nursing home.”

- 2.17 The definition and interpretation of eligibility for continuing care is approached by some PCTs through a focus on particular diagnoses (e.g. if someone has dementia or cancer), or by defining eligibility by reference to the specialist health care interventions required. Participants recounted instances where people were denied continuing health care because the required “specialist” health resource was not available locally so could not be accessed by the patient.

- 2.18 Neither of these is necessarily a needs-led approach, and while they would identify some people who should qualify for NHS continuing care, they also have the potential to overlook large numbers of people. Not surprisingly, nursing staff are often highly confused about what continuing care really means. One respondent, for example, described an idiosyncratic approach:

“I look at everyone as continuing care and then look for reasons they aren’t!”

Assessment approaches

- 2.19 How people’s needs are assessed is critical. The Single Assessment Approach (SAP) was developed following the publication of the *NHS Plan* in 2000¹³, which recognised the need for a streamlining of local assessment processes for health and social care. The approach was subsequently outlined in the National Service Framework for Older People (NSF) the following year¹⁴. The central objective of SAP is to bring about person-centred care. As the NSF described it, the aim is:

“to ensure that older people are treated as individuals and they receive appropriate and timely packages of care which meet their needs as individuals, regardless of health and social care boundaries.”¹⁵

- 2.20 SAP allows for different types of assessment which vary by breadth and depth in proportion to the needs of the older person. For a person with intensive and complex needs who is likely to require admission to a care home, intensive packages of support at home, or NHS continuing care, a comprehensive old age assessment will be required.

- 2.21 The Health Committee report on NHS continuing care raised concerns about the rate of progress with the implementation of SAP, having received evidence that practice

was highly variable. The Minister, Dr Ladyman, acknowledged to the Committee that SAP was “working better in some places than others,” and remarked that there was a need to find a way to “ensure that all older people undergo the single assessment process,”¹⁶.

- 2.22 This apparently slow progress is worrying, and was confirmed by the experience of RCN respondents. There is a significant issue of trust, and often SAP is not developing as it should because there is a lack of confidence in its approach. In particular, SAP is predicated on different health and social care professionals contributing their expertise to a multi-disciplinary process, which assumes that the integrity and validity of those inputs is accepted by all contributors. In practice, this may not be the case. For example, one respondent described a local situation in which SAP was accepted in principle, but “we still need to check” that assessment has been completed properly, and too often “we go through all the notes very carefully and we find out a lot more that has been missed”.
- 2.23 Many respondents described situations in which SAP is seen less as a process or a philosophy, and much more as simply a form or set of paper work:
- “SAP is a piece of paper [the assessment has] been written on; we need to look at the philosophy of person-centred care. If we haven’t got that right to start with, assessment is a white elephant. People are focusing on the wrong thing.”*
- 2.24 Some respondents believe one of the reasons that assessment remains poor is because of the low status afforded to older people’s care. Some respondents observed that nurses are also ‘guilty’ of devaluing the amount of nursing input that someone requires and not reflecting needs adequately in assessments.
- 2.25 There were frequent complaints about the poor quality of assessments and the low standards of information included in paper work, as well as concern about inconsistency of approach. Despite the overall framework that SAP was supposed to provide, assessment practice appears as variable as ever. Many respondents argued in favour of particular assessment tools that would encourage greater public confidence in a transparent and standard approach. At the same time, however, it was also widely recognised that any tool “is only as good as the practitioner who is doing it”, and there was no wish to reduce complex assessment to a “tick-box mentality”.
- 2.26 We return to the issues around assessment in Section 3 when we address ways forward.

The role of continuing care panels

- 2.27 The report of the Health Select Committee highlighted some concerns over PCT review and funding panels, and suggested that these serve a primary function as a gatekeeper, where “decisions are often driven by budgetary concerns rather than patient need, and clinical assessments are overturned without explanation,”¹⁷. Our research also identified a number of issues with panels. There is no single model of review and funding panel: not all PCTs use panels; some only use them to review cases where there is uncertainty about whether a person meets the eligibility criteria, while others use panels to review every recommendation for NHS continuing care. This variability is matched by a huge diversity in panels' structure and membership.

As some participants pointed out, a major reason for this is the fact that “there is no guidance on the roles and responsibilities of panel members”.

- 2.28 Some respondents described good practice in the operation of panels; for example a discharge liaison nurse commented:

“I’m on the panel, and there is a community geriatrician, a social worker and a mental health nurse. We make the decisions about continuing care on clinical grounds. We have been able to divorce provision from decisions about financial issues – we make the decision about whether or not it is continuing care first and then we look at the issue of provision. That’s how it should be.”

- 2.29 This was by no means the general experience, however. Other participants described cumbersome panel arrangements where cases could be bounced backwards and forwards over a lengthy period because of apparent inadequacies in assessment information, and as one respondent observed, “there has got to be a simpler way of doing this.”

Nature and quality of long term care

Choice in continuing care

- 2.30 The recently published Government Green Paper, *Independence, Well-being and Choice*¹⁸, sets out the Government’s vision for the future of adult social care. Central to that vision is a determination to provide choice for individuals in how they live their lives and how their care needs are met. Participants in our research told us that ‘choice’ has a very limited meaning when it comes to NHS continuing care; effectively “it doesn’t apply in continuing care”. In particular, where it is very costly to support someone in their choice to remain at home, there is considerable pressure for them to enter a care home. Respondents cite examples financial ceilings applied to packages of care in the community, and they frequently identify lack of night care as a reason someone could not receive continuing care at home. In some areas, care at home was a more feasible option for people with palliative care needs as agencies could co-ordinate other resources such as the Marie Curie and Macmillan nursing service.
- 2.31 For some authorities, the alternatives were limited by the local nursing home market, where there might be homes of variable quality or simply insufficient bed capacity. Nurses involved in arranging placements described the dilemmas in balancing choice and service quality:
- “If we know the nursing home can’t meet the patient’s needs and we allow them to go there then we are acting negligently.”*
- 2.32 Choice can be particularly limited for older people with mental health needs such as dementia, and participants also described problems in securing local alternatives for younger individuals with conditions such as Parkinson’s or Huntington’s Chorea.
- 2.33 In some areas, cost ceilings were also a feature of nursing home placements. Respondents described situations where relatives were “topping up” nursing home fees for individuals who had been assessed as meeting the criteria for fully funded continuing health care, but their home of choice was more expensive than the PCT was prepared to pay; in other words, individuals are paying for continuing care that they should receive at no personal cost. Worryingly, the research acknowledged that

people have more chance of exercising choice about a future placement “when there is an eloquent, assertive person” arguing their case.

Quality and care commissioning

- 2.34 Many nurses expressed real concern that administering the current arrangements for NHS continuing care and funded nursing care significantly detracted from planning care to meet peoples’ needs. Whilst some nurses described improvements in person-centred care planning, others were concerned that there was too much focus on an individuals’ physical care needs and not enough account taken of developing a more holistic approach to care planning:

“Nursing homes are not just about the sick and dying, nursing care is also about meeting people’s emotional needs.”

- 2.35 Several participants felt that nurses were unfamiliar with constructing detailed care or nursing plans, unlike their colleagues in social services. For example:

“Social Services are very good at care plans. Nurses have not been as good. We now need to take this on board.”

- 2.36 Another nurse commented that assessment skills were not necessarily valued or taught:

“We have moved into an assessment culture without people having the necessary skills. There is some good practice; but there is some diabolical, and people want to empire build and do things their way.”

- 2.37 Many of the participants were concerned that there was often inadequate or non-existent access to consultant supervision for people who were assessed as having complex care needs: “I doubt whether 10% of continuing care patients ever see a consultant”. This was part of a wider concern expressed about the quality of NHS continuing care that was being commissioned, as this comment makes clear:

“PCTs have much less experience of commissioning than social services do. In fact most PCTs are simply at the beck and call of the market. There is no debate about what continuing care should look like and how it should be commissioned.”

- 2.38 Models of continuing health care services remain heavily dependent on institutional care, and as such go against the grain of current policy thinking and guidance which stresses the development of community alternatives for even the frailest people, if this is their choice. While there are emerging models for community-based alternatives in some parts of the country, too often they exclude many older people, particularly those with dementia.

- 2.39 Many of the participants in the study recognised the difficulties that nursing home owners were experiencing in trying to deliver high quality care with inadequate resources. They identified two related issues: first, the need to ensure that a fair fee level is paid to care homes which adequately reflects the complexity of older people's needs. Some PCTs have adopted the local social service contract level to set their own contract price for continuing care. It can also be very difficult for home owners to plan effectively when their income levels fluctuate due to changes in residents’ entitlement to continuing care or RNCC determinations.

- 2.40 The second issue concerned problems with recruitment and retention of appropriately qualified staff:

“They can’t retain nurses on social services contract level, the (...) Centre is down the road and nurses get more money working there.”

- 2.41 All the participants were concerned about the quality of continuing care available. Health and social care agencies in both the public and independent sectors were described as chasing the same limited pool of staff. So all services were stretched, and this impacted particularly on those areas trying to develop 24 hour community-based alternatives. Where good working relationships had been established across health and social care commissioners, nurses described situations in which patients who became eligible for fully funded care could continue to be supported in the community by the NHS (through use of Section 31 payments), without this causing any disruption in the existing package of care or staff. However, where commissioning was less integrated and boundary disputes more evident, community placements had broken down when social care staff had been withdrawn once an individual was assessed as requiring continuing health care.

- 2.42 The research identified that while the requirements of the revised continuing care guidance and the RNCC framework may have resulted in more regular reviews of individual care plans, there remains a lack of systematic monitoring of the continuing care services which are being commissioned, nor is there any indication that services are the subject of regular clinical audit to assess their effectiveness. As one respondent remarked:

“We place the sickest and most dependent people into the hands of the least qualified and leave them to it.”

RNCC interface issues

- 2.43 The Health Committee report on NHS continuing care drew attention to the widespread confusion that exists between the two parallel systems of NHS continuing care, and funded nursing care. This was a recurrent feature of evidence submitted to the Committee’s inquiry, including the memorandum from the Royal College of Nursing:

“The RCN believes that there is also a need to re-examine the link between funding for NHS continuing care and the top band of nursing funding. Under the current system, there is a lack of consistency and understanding about those needs that trigger continuing health care and those that trigger the top band of funded nursing. The boundary between continuing health care and NHS funded nursing is unclear, which may be due to similar terminology being used in both sets of criteria.”¹⁹

- 2.44 The Department of Health has exchanged correspondence with the NHS Ombudsman on this matter which indicates that the development of a national framework for NHS continuing care will “include NHS funded nursing care”, and this will provide an opportunity to clear up any existing confusion.
- 2.45 Given that these interface issues are widely recognised as problematic, it was not surprising that this also emerged as a central theme of our research. Our on-line survey explored issues that need to be resolved in continuing care, and distinguishing

between top band RNCC and fully funded care was identified as a major concern (see Appendix 1).

Confusion between RNCC and fully funded care

- 2.46 It was emphasised repeatedly that the High Band of RNCC is often indistinguishable from NHS continuing care. Guidance on RNCC defined eligibility for High Band as:

“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.”²⁰

- 2.47 Clearly, there is enormous similarity between this definition and that for NHS continuing care eligibility, and so the basis for confusion is clear. This can lead in practice to people being denied access to NHS continuing care. Despite the fact that guidance from the Department of Health has emphasised that assessment for continuing care should always be undertaken *before* people’s needs for registered nursing are considered, in reality it is too often the case that the process is inverted. When health and social care staff have a poor understanding of the relationship between the two systems, people will often be referred to the RNCC assessment team for determination of their needs for registered nursing input and nursing home placement, without any consideration of whether they might in fact qualify for fully funded continuing care. The following comments were typical of many that were made:

“People don’t understand the differences between funded nursing care and continuing health care. People who should know better see it as more of the same. It’s not more of the same; it’s about health needs, not health inputs!”

“It makes sense to professionals but it is incomprehensible to relatives – it feels unjust to them.”

- 2.48 The Health Committee concluded that it is “a nonsense” to have two separate systems operating alongside each other, and expressed surprise 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.”²¹

- 2.49 As some of the participants in the research pointed out to us, the reasons for these separate systems reflected “a purely political decision to fund nursing care”. The RNCC arrangements were introduced as part of the Government’s response to the recommendations of the Royal Commission on Long Term Care, and this incremental adjustment to policy has had far-reaching and apparently unforeseen negative consequences.

- 2.50 Several respondents drew attention to the sheer cost of running two systems: example:

“I think the other thing with the RNCC is the cost of operating it and administering it. The cost of setting it up initially and all the work in running it is phenomenal. There is

all this additional paperwork; we are running ourselves ragged – and for what? It is not the client who benefits from any of this! It is just so the Government can say that it has fulfilled its commitment to provide free nursing care.”

And:

“We have created a whole new bureaucracy (around RNCC) in terms of funding, charging and invoicing.”

2.51 The question of who benefits from the RNCC payments is an important one. Often it appears that the value of RNCC is not passed on to the client because nursing homes simply increase their fees by an equivalent amount. There were also reports of homes that will only accept people who are assessed on the higher banding because they are trying to maximise income.

2.52 Many participants took issue with the way in which RNCC payments were often referred to as ‘free nursing care’, and were highly dismissive of the implication that these payments could cover the real costs of providing nursing care. With effect from 1 April 2005, the low, medium and high bandings are worth respectively £40, £80 and £129 per week. As this respondent observed:

“The middle band funds about 40 minutes of nursing care a day. If someone is on 3 medications, 4 times a day, it will just about fund the medicine round.”

2.53 The inadequacies of the RNCC to cover full nursing costs are a particular concern for independent sector nursing homes. A nurse proprietor explained:

“We have to give people the care they require, not what the banding indicates, unless we are going to neglect residents. When people’s needs change, by the time they re-band them it is too late; we can’t just suddenly bring in more staff to meet extra needs.”

2.54 This also raises issues about how the nursing input is defined. From the point of view of the RNCC, only nursing that requires the input or supervision of a registered nurse is counted. However, as many participants pointed out, the definition of nursing is one that has changed over time, and it makes little sense to define it in terms of who provides it, for example:

“People who are giving care often say that a person is highly dependent – they are getting a lot of input, but most of it is not from registered nurses. When we all started nursing, care was nursing, but political agendas have now separated that out.”

Perverse incentives

2.55 There are issues about the apparently perverse incentives that arise in the system. Participants widely acknowledged these, and the issue was also identified in the report by the Health Committee. The banding system provides insufficient recognition of the nursing inputs that are required to maintain a resident at a particular level of function, or quality of life. If, for example, a person is allocated initially to high band, but subsequently it is judged that their needs are now only medium band, reducing their RNCC funding will effectively reduce the amount of nursing input they receive and may well lead to deterioration in their condition. The following comments illustrate these difficulties:

“Even those with low needs are receiving a level of input that sustains them; the system doesn’t reward that care.”

“When someone is stable it is because of the care environment and inputs they are receiving.”

- 2.56 In some instances it was acknowledged that the RNCC process is a purely academic or paper exercise that actually makes no difference at all to the input that a resident receives, and many “don’t ever see a registered nurse,” whatever level of registered nursing needs they have been assessed as having.
- 2.57 Several respondents felt the answer to these difficulties was a simplification of the system, and – at the very least – a reduction of the three banding system into a flat rate, such as operates in Wales.

Experience with the review and restitution process

- 2.58 Following the Ombudsman’s decision in the Coughlan case, SHAs were required in 2003 to investigate whether anyone in their area had been wrongly denied continuing care, either because the criteria that were being used were wrong, or because they had been wrongly applied. This retrospective review process also required financial restitution to be made in those cases where people had been wrongly denied NHS continuing care. Many of our participants had been involved in the review and restitution process and were anxious to share their experiences. The process was variously described as “a great victory for patient entitlement” and “a nightmare,” and for others raised expectations that could not be met.
- 2.59 All were in agreement that the process was “extremely stressful” for both staff and relatives. Most nurses directly involved undertook the reviews in addition to already busy full-time jobs, resulting in long hours often with no additional recompense and a significant encroachment into family life. As one nurse assessor commented, “my dining room table was out of action for months!”. The findings from our on-line survey similarly identified the workload pressures associated with involvement in review and restitution.
- 2.60 The process involved going back through old records which were often difficult to find and a significant proportion of older people had already died by the time the review was instigated. Respondents recounted stories of records which had been destroyed, nursing homes which had closed making the location of personal records particularly difficult, and hospitals which had neither the time nor inclination to research old records for relevant information. For many of those involved, “the whole review and restitution thing was not well handled”. The following comment was typical:
- “It was a shambles. It was clear that there were cases going back years where people had never been assessed for continuing care. The public were very muddled.”*
- 2.61 Such findings are consistent with the conclusions of the national review²² and with the report of the Health Committee.
- 2.62 While respondents indicated that the review process had resulted in “ferociously aggressive relatives who blamed them personally for the wrong decisions,” in general

the nurses were aware of how stressful the exercise was for these relatives. As one respondent commented:

“It was very stressful for relatives, they had to revisit painful issues, particularly if their relative had died and panels could be intimidating, even if they tried not to be.”

Another commented that for some relatives, particularly if they were given support, the process was “the first time (they) got to tell their stories, it could be cathartic”.

- 2.63 There was general agreement that the review and restitution process had often unfairly raised public expectations and resulted in a more combative relationship between professionals and older people and their relatives. Some members were particularly critical of the press in unfairly raising expectations, as in this comment: “There was therefore a lot of public expectation that was ill-served by the *Daily Mail*.”
- 2.64 In the wake of the process, respondents were concerned that determining continuing health care needs would be more difficult and confrontational, with relatives becoming upset, particularly if people’s assessed dependency was revised downwards. Some of the nurses, however, felt that relatives were often unfairly portrayed as only interested in money when they complained or appealed, whereas a range of motivating factors may have applied. For instance, families may:
- feel that their relative has a right to free care as they have “paid their dues”
 - be concerned that their relative is ill and needs nursing care
 - have concerns that they are losing their inheritance.
- 2.65 Respondents generally believed that this latter group was the smallest in number. Despite this, the unfortunate reaction of many health care professionals seems to have been an assumption that restitution was just about “the family being greedy”.
- 2.66 Respondents in the study were concerned about the costs of administering the review process. They also feared that the inadequacies of current eligibility criteria might mean a repeat of the review and restitution process was likely in the future, if progress was not made towards introducing national eligibility criteria. The time taken by the process had, in the view of some respondents, detracted from their ability to concentrate on developing more robust models of continuing care.
- 2.67 Some of those who had been involved in the review process learnt some hard lessons, as this comment demonstrates:
- “Note keeping was appalling. I have to say that as a nurse I was ashamed. I really hadn’t expected that. The best notes and record keeping we came across were from social services. We have got a lot to learn about developing clear documentation.”*
- 2.68 For others, the role of the SHA had been problematic:
- “A lot of decisions got over-turned by the SHA. It seemed that if you had really loud relatives you would probably be OK. It was all very, very difficult.”*
- 2.69 The retrospective review process undoubtedly caused many difficulties and challenges for those who were closely involved. It was often a demanding and distressing experience for staff, patients and relatives alike. Despite this, there was satisfaction in being able to achieve restitution for some clients. The audit of past

practice that the review provided was also seen as very important in bringing to attention many issues to be tackled to improve the consistency and quality of assessment and decision-making in the future.

In conclusion

- 2.70 It is striking that a high degree of consensus characterised many of the discussions with RCN members about key themes. The views and reflections that we have summarised were typical of those we encountered. What is also clear is that contributors were very anxious to see change and welcomed the opportunities that could arise from the forthcoming national approach to continuing health care.

Section 3: Conclusions and ways forward

- 3.1 For many RCN participants, the underlying principles and values that motivate their work reflect a belief that all nursing *and* personal care should be free of charge. Some were less convinced that this was necessarily the solution, and raised questions about whether the arrangement which has been followed in Scotland is working as well as people had thought it would. However, what did attract widespread agreement was the belief that access to NHS continuing care should be *fair*. A number of specific conclusions flow directly from this fundamental conviction.
- 3.2 If there is to be greater fairness in continuing health care, there are clearly some important messages that should inform the development of the new national framework - so this RCN report is especially timely in contributing to the debate. There are also some messages for the RCN itself to consider, not least about how it promotes the modern role and responsibilities of nurses. We turn now to summarise key reflections on ways forward.

Developing a national approach

- 3.3 There was strong support among RCN participants for the development of a genuinely national approach to continuing health care across England. As a minimum, this should include development of standard national eligibility criteria in order to end the problems of the 'postcode lottery' of care. Our research indicated that particular attention would need to be paid to:
- clarity of definition and simplicity of terms, to ensure that the criteria can be easily understood and consistently applied
 - comprehensiveness of approach, to adequately address the wide ranging needs of different client groups, and giving equal weight to psychological and mental health dimensions as to physical care needs
 - significant awareness-raising and training, to improve understanding of the role and contribution of continuing health care throughout the health service, and to ensure that the triggers are in place to identify people with continuing health care needs and to assess these appropriately.
- 3.4 The research also showed that tackling continuing care criteria alone would make little sense for many RCN members, unless there was corresponding attention to needs for registered nursing care. These issues were identified strongly in the on-line survey, and amplified in group discussions and individual interviews. The RNCC system was viewed by many participants as increasingly anomalous and the cause of many difficulties. Not least, it is clear that the principle that assessment for NHS continuing care should always precede that for RNCC is widely flouted, and this in itself denies many patients access to fully funded care because their eligibility is never assessed.
- 3.5 The reasons why the RNCC system had come into being were well understood by participants. As many people remarked, however, if you were designing a system from scratch it wouldn't look like this. The potential for confusion, overlap and omission between the two parallel systems is legion. If the two systems *are* to continue, the findings from our review indicate strong support for tackling:

- the definition of eligibility for RNCC and NHS continuing care. These must be more clearly distinguished, and the similarity of wording and use of identical terms in determining eligibility for both must be resolved
- a fundamental reconsideration of the way in which the RNCC is defined. The present approach represents a minimal contribution towards the real costs of nursing input and defines nursing in terms of who provides it rather than by reference to the needs of the patient
- a consideration of the logic for maintaining three bandings for RNCC. There are considerable difficulties associated with the bands, including some apparently perverse incentives. One way forward could be to consider whether it might be easier, less costly and bureaucratic - and more acceptable - to adopt a flat rate payment.
- how to ensure that the value of the RNCC is passed to the patient and does not simply become absorbed by care home charges. This must also recognise that those with assessed higher care needs *will* require care that will inevitably cost more than care for those with lower needs.

Needs assessment

- 3.6 However good a national framework and eligibility criteria for continuing care might be, our participants recognise that in practice much will still depend on how those criteria are interpreted and applied, and how needs are assessed. There was general support for the development of tools and methodologies that might assist with the technical task of assessment. At the same time, RCN respondents were extremely cautious about following a 'tick box' approach that would reduce assessment to an over-simplified, mechanistic process. To a large extent, the desire for some technical help with assessment can be seen as a reflection of the frustrations with the slow development and adoption of the Single Assessment Process. Most people supported the philosophy of SAP, but were hesitant to trust it. This is therefore not necessarily an argument to reject SAP and start again, but to ensure that the development of SAP becomes a greater priority, and that the cultural and environmental changes required to support it within both the NHS and social care systems are addressed.
- 3.7 There was no consensus over a *particular* tool that should be used, although several different methodologies are clearly in use around the country. For RCN members the over-riding concern is to have a tool that works and that can ensure the needs of older people and others with needs for continuing health care are properly and speedily assessed.

Developing the necessary skills

- 3.8 While RCN respondents were generally in favour of central direction in the area of assessment, and supported a national tool, most also emphasised that improvements in practice would only result if the important role of professional judgement in assessment was recognised and promoted. Our respondents also stressed the importance of training and awareness-raising, as summed up by this comment:

“A multi-disciplinary approach is needed. It’s fine with specialist nurses – we know the criteria, but its when others are also involved that there are problems. There has to be training for everyone”

Improving understanding

- 3.9 The challenge for local health and social care economies is to embed into everyday practice an understanding of what is meant by continuing health care and funded nursing care. Hospital staff often present particular challenges. It was remarked frequently that “all acute staff should be able to identify potential continuing care cases, but often people have no idea”. There have been efforts to tackle these difficulties and participants shared with us examples of where a set of triggers based on the continuing care eligibility criteria had been developed for use by hospital staff in screening patients. This approach was seen to be particularly successful when communicated as part of a wider, multidisciplinary training package.
- 3.10 Training will need to be a key component in the roll out of the proposed national framework for continuing care. Our respondents saw PCTs taking a lead in identifying resources to ensure this happens, but recognised the need for acute trusts to prioritise this agenda more than is currently the case. As one respondent remarked to us, for example:

“The trouble is, as people cascade things – it gets diluted.”

Improving assessment skills

- 3.11 Concerns were expressed to us about the lack of value attached to assessment skills. Nurses told us frequently that they believed holistic assessment should be the norm and that assessment processes should take account of psychological as well as physical needs. When national training material is being developed it will need not only to familiarise staff with the assessment tool to be used, but also to set the broader ‘culture’ in which assessment should take place. Increasingly, the emphasis is on establishing a partnership with older people (and their carers) as part of the assessment process and promoting choice and control. These values and principles need to be reflected and embedded in the continuing care assessment arrangements.

Developing effective care plans

- 3.9 Care planning in continuing health care was described frequently as poorly developed, and even non-existent. We need a clearer view of what constitutes effective care planning for people requiring continuing health care, one which clearly links assessed needs with appropriate individual programmes of care. Some of our respondents talked about developing ‘nursing prescriptions’ or plans which detailed the care required by individuals following the analysis of the assessment information, with these plans used as the basis for regular review with nursing home staff.
- 3.10 When care plans are developed they are often not shared routinely with older people themselves or their relatives, and on occasions not even with the care home staff where a placement has been made. The findings from the research indicate that there is a need for care plans:
- to reflect fully the assessed needs of individuals

- to be developed in conjunction with, and jointly owned by patients and their relatives
- to form the basis for arranging, delivering and monitoring the care package.

It is only then that progress will be possible towards more person-centred care for the most dependent and frail people in society.

Understanding the nursing contribution

- 3.11 Some of the difficulties encountered in ensuring high quality assessments and care planning were attributed by our contributors to the fact that nurses often fail to appreciate the value of their own skills and inputs to a patient's care and do not define these as nursing. This appears to be linked to a more fundamental issue regarding the status of nursing older people, as indicated by this remark:

"There is a widespread view (even among nurses) that older peoples' care is not skilled and anyone can do it."

- 3.16 This state of affairs is believed to have resulted in part from the efforts of the nursing profession to achieve greater recognition alongside the medical profession, and also reflects the developments associated with *Agenda for Change*. Increasingly the image of nursing is one focused on high-tech interventions and advanced practitioners. There appears to be a danger that the *care* element associated with nursing older people may get lost or at least undervalued. As one participant remarked:

"It links into the whole debate about what nursing is – all that stuff around too posh to wash!"

- 3.17 Many people who require continuing care do not need complicated technical interventions, but the care and support they receive is no less valuable or crucial in ensuring that their needs are met effectively. As another of our contributors commented:

"We have lost the art of nursing: we want to see it all as a science, and all the care has been thrown away."

- 3.18 The RCN has a key role in promoting the value of nursing older people. Its strategy document, *Caring in Partnership: older people and nursing staff working together towards the future*²³, presents a framework for focusing efforts on combating ageism, working in partnership with older people and their carers, and developing evidence based practice. The challenge for the RCN will be to promote the messages in the document and secure wider ownership within its membership.

Improving the quality of long term care

- 3.19 Our discussions with RCN members highlighted the importance they attach to improving the choices available to people requiring continuing care and to the standard of the care available. Respondents to the on-line survey similarly identified the quality of care offered as a high priority. The health care professions need to

develop a greater understanding of what constitutes good quality continuing care and how this can be commissioned most effectively. It is unlikely that quality can be addressed without also considering in more detail what constitutes a fair price for care.

- 3.20 Our research has confirmed the lack of choice available for many people with continuing health care needs. We recognise that work is underway in many parts of the country to develop community alternatives to nursing home care, but cost still appears to be the major determinant of whether people can be supported in the community. Working in new ways requires people to be flexible and creative, not least in considering the human resource implications of new models of working. We were especially interested to hear of progress being made. For example, in one area of Wales we were told there are:

“Large numbers of community packages even for people who are fully funded continuing care. We train our own health and social care workers – they are C Grade nurses with NVQ level 3 and they can do health and care tasks.”

- 3.21 Another nurse was proud of her success in putting together a flexible community package for a patient with Motor Neurone Disease:

“(She) is being fully funded at home to the tune of £18,000 a month. I am really proud we are paying for her – but where else could you put a 31 year old on a ventilator? She is extremely difficult to maintain but people like her get ignored in all this debate.”

- 3.22 Efforts need to continue to develop community alternatives for people with continuing care needs who do not want to move into a care home. Increasingly models of care are being developed including specialist nursing teams for people with dementia. These need to be promoted more widely.
- 3.23 During this study we also heard about the development of closer working relationships between nursing home managers and their staff, and RNCC nursing teams. Relationships appear to have developed partly as a result of the need to work together more closely in making RNCC determinations, but also through more contact during individual reviews. In some areas resources have been specifically allocated to facilitate support to nursing home staff, including identifying their training needs and delivering programmes to meet these. Some teams are multi-professional and are able to offer nursing homes easier access to consultant support and specialist nursing input. Where such teams are in operation, RCN members indicated that they were able to support residents for longer, avoiding unnecessary hospital admissions.
- 3.24 Promoting choice should be a priority for those with a responsibility for developing and commissioning continuing care. We have sufficient examples of effective community alternatives to begin to influence commissioning intentions. Unfortunately, the debate to date has been disproportionately focused on eligibility criteria and gate keeping, and it is now time to concentrate on how we are actually meeting people’s needs in the longer term. Nurses have an important contribution to make through focusing on improving assessment and making it more person-centred, and in developing more holistic care plans. These developments must be underpinned by effective multidisciplinary working and adequate support to care providers.

Conclusion

- 3.24 The objectives of this research, carried out over a short term, was to provide a sample of the views of RCN members on continuing health care for older people. The research was undertaken at a time when these issues are once more on the political agenda. This new interest reflects a number of factors which have followed upheaval in the wake of the Ombudsman's report and the subsequent retrospective review and restitution process. The subsequent statement by the Minister that a new national framework would be developed has also been followed by detailed scrutiny of continuing health care by the House of Commons Health Committee.
- 3.25 The findings from the research are consistent with those of other recent work. What is distinctive about this report is that it reflects the particular perspectives of nurses. This is a highly informed and experienced viewpoint, and the nurses who participated offered invaluable reflections from their day-to-day practice.
- 3.26 We have highlighted a number of areas in which our members have grave concerns about continuing health care. We have also identified some positive ways forward. There are opportunities for the RCN to take these findings and use them to contribute to the emerging debate on the national framework. There is potential to move beyond often sterile arguments, and to focus instead on an approach that is grounded on principles of fairness and equity, and seeks to deliver a consistent, individualised, high quality and flexible model of care fit for the twenty-first century.

References

Section 1

- ¹ Secretaries of State (1989), *Caring for People: Community care in the next decade and beyond*, Cm 849, para 2.5, London: HMSO.
- ² Report of the Health Service Commissioner (1994), *Failure to provide long term NHS care for a brain damaged patient*, Second report for session 1993-94, London: HMSO.
- ³ Department of Health (1995), *NHS Responsibilities for meeting Continuing Health Care Needs*, HSG(95)8. LAC(95)5.
- ⁴ Department of Health (1999), HSC 1999/180 *Ex parte Coughlan: Continuing health care follow up action to the Court of Appeal judgement in the case of R v North and East Devon Health Authority*.
- ⁵ Department of Health (2001), *Continuing Care: NHS and Local Councils' Responsibilities*, HSC 2001/015. LAC(2001)18.
- ⁶ Secretary of State for Health (2000), *The NHS Plan: The Government's response to the Royal Commission on Long Term Care*, Cm 4818-II, London: The Stationery Office.
- ⁷ Sir Stewart Sutherland (1999), *With Respect to Old Age: Long term care – rights and responsibilities. A report by the Royal Commission on Long Term Care*, Cm 4192-I, London: The Stationery Office.
- ⁸ *NHS Funded Nursing Care Practice Guide & Workbook* (2001), Department of Health.
- ⁹ The Health Service Ombudsman (2003), *NHS Funding for Long Term Care*, HC 399, para 38.
- ¹⁰ Melanie Henwood (2004), *Continuing Health Care: Review, revision and restitution*, Department of Health.
- ¹¹ New national framework on continuing care, written ministerial statement, 9th December 2004.
- ¹² House of Commons Health Committee (2005), *NHS Continuing Care*, Sixth report of session 2004-05. HC 399-1, London: The Stationery Office.

Section 2

- ¹³ Secretary of State for Health (2000), *The NHS Plan: A plan for investment. A plan for reform*. Cm 4818-I, London: The Stationery Office.
- ¹⁴ Department of Health (2001), *National Service Framework for Older People*, London: Department of Health.
- ¹⁵ *Ibid*, P.23.
- ¹⁶ House of Commons Health Committee (2005), *NHS Continuing Care*, Sixth report of session 2004-05, Para 108, London: The Stationery Office. HC 399-I
- ¹⁷ House of Commons Health Committee (2005), Para 148.

¹⁸ Department of Health (2005), *Independence, Well-being and Choice: Our vision for the future of social care for adults in England*, Cm 6499, London: The Stationery Office.

¹⁹ Royal College of Nursing (2005), *Royal College of Nursing memorandum to the Health Select Committee Inquiry into NHS Continuing Care*, Para 5.6.

²⁰ Department of Health (2001), *NHS Funded Nursing Care. Practice guide and workbook*. London: Department of Health.

²¹ House of Commons Health Committee (2005), *Op Cit*, Para 97.

²² Henwood M (2004), *Continuing Health Care: Review, revision and restitution*, Department of Health.

Section 3

²³ P Ford, E Waddington (2004) "*Caring in Partnership: older people and nursing staff working towards the future*" London: RCN. Publication code 002 294.

Appendix 1 NHS Continuing Care: *Summary of Findings from an on-line survey of RCN members*

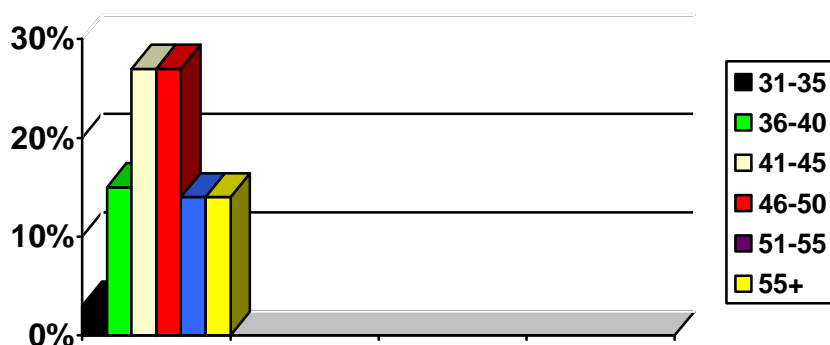
On-line survey

An on-line, confidential survey on continuing health care was made available through the RCN website, www.rcn.org.uk. The survey was accessible to members from the 7-28 February 2005, and in this period 66 returns were made. This was a considerably higher number of responses compared with other on-line surveys operated by the RCN.

The survey respondents

Survey respondents came from all RCN regions (including Scotland and Wales), with the highest proportions from the South West (20%), the West Midlands (18%) and the South East (17%). Just over 90% of respondents were female, and the age distribution is summarised in Figure 1.

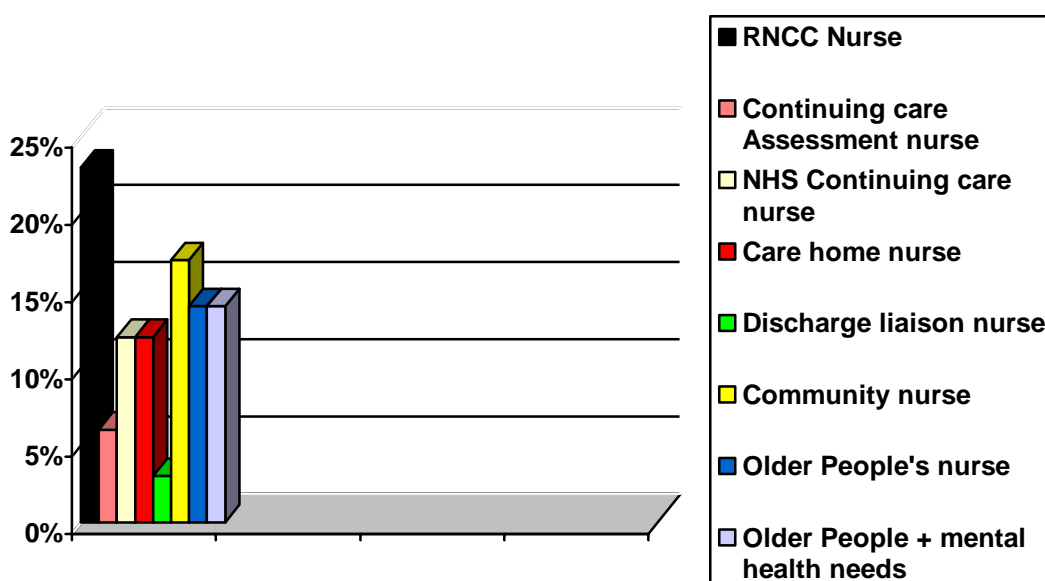
**Figure 1:
Age of respondents**



As the figures indicate, respondents were mature and experienced. More than half were aged between 41-50, and a further 28% were at least 51. This depth of experience was also evident in the professional grades of respondents. The highest proportion of respondents were Grade G (29%), and overall almost three quarters (73%) were Grade G or above.

Respondents brought a range of experience that was especially relevant to the topic of continuing health care. Almost one in four (23%) were RNCC nurses. The distribution of other roles is presented in Figure 2.

**Figure 2:
Roles of respondents**



A new national approach to continuing care

On 9 December 2004, the Minister Dr Stephen Ladyman made a statement indicating that a new national approach to continuing health care would be developed in order to improve consistency and ease of understanding. The on-line survey asked respondents to indicate what they believed needed to be addressed in this national approach.

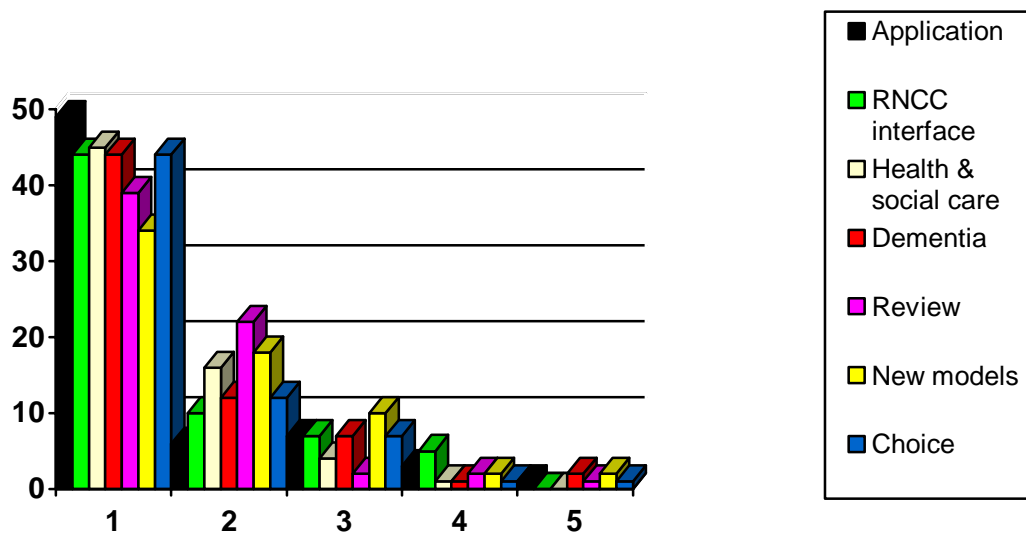
Respondents widely endorsed the need for national eligibility criteria. Almost as much priority was given to the need for a national assessment framework or tool to support implementation, together with appropriate training and development. Almost 60% of respondents also indicated that the framework would need to address the interface between NHS continuing care and the Registered Nursing Care Contribution (RNCC, the banded payment to cover registered nursing care costs for nursing home residents).

The survey asked respondents to rank in importance a number of issues needing to be resolved around continuing health care. These addressed the following issues:

- application and interpretation of criteria at local level
- distinction between top band RNCC and fully funded NHS continuing care
- understanding respective responsibilities of the NHS and social services for long term care
- how the needs of patients with dementia are addressed by continuing care eligibility criteria
- need to develop new models of continuing care
- attention to choice for patients needing continuing care.

The results are presented in Figure 3; the rankings are from 1 (most important) to 5 (least important).

Figure 3
Ranking of issues to be resolved in continuing health care



As the figures indicate, the most highly ranked issue concerned the application and interpretation of criteria at local level. Four issues then clustered closely together (understanding health and social care responsibilities, distinguishing between top band RNCC and continuing care, addressing the needs of patients with dementia, and choice in continuing care). Relatively less priority was allocated to the need for regular review, and the development of new models of continuing care was ranked least important of the seven issues.

Equity, quality and understandability

A further ranking was undertaken asking respondents to rate the importance of a range of factors relating to principles of equity, quality and understandability. These were:

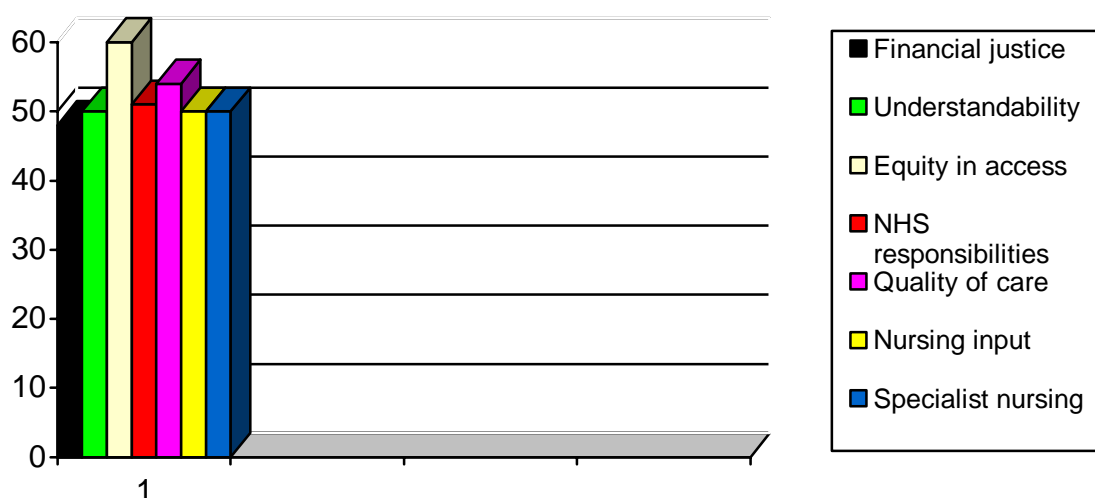
- ensuring people needing long term care do not experience financial injustice
- ensuring that the public can understand criteria for continuing health care
- ensuring equity in access to NHS continuing health care
- ensuring the NHS fulfils its responsibilities to provide continuing health care
- addressing quality of care in continuing care
- ensuring the nursing input to NHS continuing care is sufficient
- recognising the specialist nursing skills required to deliver continuing health care.

A comparison of top rankings (see Figure 4) indicates considerable clustering and similarity of priority across these issues.

It might be argued that there is not always consistency of response. Thus while more than 90% of respondents ranked equity of access to NHS continuing care across all primary care trusts (PCTs) as very important, fewer than three quarters gave the same priority to ensuring financial justice. 'Equity' in this sense is concerned particularly with the desire that people who happen to live in different locations should not be disadvantaged compared to others, because criteria vary between SHAs or they are differently interpreted and applied by different PCTs.

The second most highly prioritised issue (identified by almost 82% of respondents as very important) concerned the need to address the quality of care provided in continuing care settings.

Figure 4
Prioritising of equity and quality issues



Review and restitution

During 2003-2004 the Department of Health required all SHAs to review the way in which criteria for continuing health care had been applied since 1996, and to make retrospective financial restitution in those cases where it was found that the criteria were wrong or had been unfairly applied.

Almost a quarter (24%) of respondents had been directly involved in the process of review and restitution. Almost all of these indicated that this involvement had a significant impact on their working practice. Comments particularly reflected the nature of workload pressures, for example:

“Huge increase in workload and responsibility for myself and senior nurses within my team.”

And:

“Required to take on additional work regarding these cases, with no additional resources.”

Some respondents recognised the value of the exercise, for example, “It highlighted the need to document care accurately and comprehensively”. At the same time, others also commented on the difficulties they faced, for instance: “it made working very stressful and there was a lot of pressure from families”.

These issues were explored in greater depth by asking respondents to indicate their agreement with a number of possible statements. Of those who had been involved in restitution, respondents were far more likely to identify negative aspects of the experience.

- 84% of these respondents agreed strongly that this had been a very stressful, demanding and time consuming process
- similar proportions (79%) believed that the process had unfairly raised people’s expectations and then disappointed them
- despite this, only 5% believed the exercise to have been a waste of time, but only the same proportion believed that it had enabled the NHS to resolve issues and uncertainty and provide a better foundation for improved understanding
- in terms of the perceived benefits to patients and their families, less than a third of respondents involved in restitution believed it had been an important exercise that rectified injustice for many people, and only around a fifth believed it to have been important in allowing people to feel they had been listened to.

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