

Department of Health consultation on the National framework for NHS continuing healthcare and NHS funded nursing care in England

Response by CCC

Introduction

CCC is a unique coalition of commercial, charitable and public service organisations with a mutual interest in seeking the best possible care for current and future generations of older people. CCC's [members](#) include care and housing providers and commissioners, trade and professional bodies, financial service providers and providers of information, advisory and advocacy services for older people. CCC, founded in 1992, was known as the Continuing Care Conference until 2004.

CCC welcomes the opportunity to comment on the proposals contained within the consultation on the national framework for NHS continuing healthcare and NHS-funded nursing care in England. CCC's consultation response draws on and distils the experience and views of its members. Several members will be submitting their own detailed responses.

Overview

While welcoming the Department's proposals for a national framework as a genuine attempt to make improvements to the care system, CCC has concerns about various aspects of the proposals, as detailed below. In short, CCC believes that no less than a root and branch reform of the present system of social care funding is required.

Simplicity, transparency and absolute clarity in relation to who is responsible for the costs of care are fundamentally important considerations for CCC. CCC has consistently recommended the adoption of a single national assessment instrument to ensure equity of access to appropriate levels of care and support.

Responses to Specific Consultation Questions

- 1. The Department of Health recognise that terminology can be complex in this area, and the names given to particular packages of care (for instance, 'NHS Continuing Healthcare') can cause confusion. Do you have any suggestions for how these core concepts could be re-named to better describe the services they provide?**

CCC would welcome clear consistent terminology that is understandable to the public at large but does not offer any suggestions at this stage.

CCC members have great difficulty with the core concepts and consequently their terminology because CCC believes that the care system is fundamentally wrong.

CCC strongly believes that fractured budgets are not the way forward. There should be a continuum of care with clarity about what the state will provide and what the individual will be means tested for. There should also be a progressive state contribution related to need not a variable personal contribution, unless a level of dependency and complexity of need has been reached that removes all personal obligation and results in fully funded care.

At present, nursing homes are not generally funded to provide end-of-life care. CCC recommends that care homes should be increasingly resourced to provide end-of-life care, which would reduce the need for hospital admissions at such a time.

Increasingly the dementias are the drivers for increasing care and there is still a failure to recognise the clinical risks and management needs that these citizens require. Rather than requiring purely social care, they have important health issues that deserve an integrated care solution.

- 2. Currently, Strategic Health Authorities hold policy responsibility for local Continuing Care policies. Following the introduction of the National Framework, the Department of Health are considering moving this overall responsibility to Primary Care Trusts as the local commissioning bodies for NHS services. What are your views on this proposal, and are there any particular benefits or potential obstacles to achieving this?**

Questions of monitoring and appeals are important in this context. CCC believes that the importance of contestability cannot be underestimated.

If overall responsibility is moved to PCTs, PCTs will need to be monitored by Strategic Health Authorities.

CCC has concerns that if responsibility is at local level the appeals system may be unwieldy. Independence is required. As well as independence, flexibility is important for the monitoring and appeals process.

It is not clear who would run the appeals system – the Healthcare Commission or the amalgamated Healthcare Commission and CSCI. Whatever, we believe that a clear and flexible appeals system is more important than which organisation administers it.

CCC's members also emphasised the following issues in the context of the question:

- An assessment may conclude that a resident may need to move. Any decision-making must take into account the considerable and well-documented risks of moving residents. To minimise such risks, enabling residents to stay in their current surroundings or to choose a higher quality of care, CCC advocates that it should be possible for families to top-up NHS fully funded care in care homes (this is no different in principle than NHS patients electing to pay for a television or bedside phone whilst in an NHS hospital).

3. The National Framework sets out to assess individuals on the basis of their need for care, rather than their diagnosis, condition or where the care is provided, as the fairest way to determine eligibility for NHS funding. Does it achieve this or are there other factors which should be considered?

While welcoming a needs-led approach, CCC contends that the above basis is not the fairest way to determine eligibility for NHS funding and that other factors must be considered. CCC also believes that there should be no perverse incentives to detract from good care practice. Obvious examples are preventative and proactive approaches to care and risk minimisation.

Diagnosis: Diagnosis should not only be considered but should be a fundamental consideration. Factors such as complexity and unpredictability are, to an extent, determined by diagnosis. For example, the pattern of need and consequently care following a single stroke or Parkinson's disease, and its progression, are likely to differ greatly. A census by CCC has confirmed that diagnosis of specific clinically driven disability is the greatest determinant for continuing care generally (see below).

Place: To the extent that the assessment takes support and support needs into consideration, it should take account of where the care is provided. That said, CCC members have reported examples of where, in the past, care in a nursing home has acted against the individual receiving continuing care funding to which they were entitled. Place should not be used as a means of denying eligibility.

Well-being: Assessment should not ignore the well-being of the resident. The importance of well-being is underlined by its presence as a core concept of DH's Social Care Green Paper, *Independence, Well-being and Choice*, and CSCI's stated aim for the inspection system to be linked to outcomes arising from the Green Paper.

Care home population: The National Framework should be cognisant of the characteristics of the population resident in care homes and using care services. In March 2006, CCC undertook a census of care home residents which mapped the care needs of over 32,000 people resident in 751 care homes across the UK. The census, undertaken by CCC care provider members, expanded upon the findings of BUPA's 2004 care home census. CCC is keen for the census approach to be repeated and extended in future years to ensure that policy planning reflects evolving needs.

The 2006 census found that:

- 89% of residents had required care as a result of the disabilities arising from long-term medical conditions
- 54% required care related to dementia, stroke or Parkinsonism
- 72% of residents were immobile or reliant on assistance
- 62% were confused or forgetful
- 24% were confused and immobile and incontinent

The census highlighted the impact of chronic diseases including Alzheimer's disease and stroke.

The RNCC funding arrangements were compared for three areas in England. The percentages of residents who were confused, immobile and incontinent (ie with demonstrably complex care needs) and who received RNCC funding were as follows:

Band	Area 1	Area 2	Area 3
RNCC Band 1	0%	1%	7%
RNCC Band 2	40%	52%	57%
RNCC Band 3	5%	12%	4%
Total with RNCC funding	45%	65%	68%

(NB: The areas compared, Birmingham, Liverpool and Kingston, were not identified so as to maintain anonymity.)

4. The Department of Health assess whether an individual’s primary need is a health need with reference to four key indicators – nature, complexity, intensity and unpredictability. Do you think these are the correct indicators, or are there any omissions?

CCC has concerns that the terms are not necessarily easily understood, with consequent confusion and anxiety for older people and those concerned with their care.

When an individual or their family is given a diagnosis of a condition that is incurable and that their condition will deteriorate it is very difficult to accept the logic that NHS care support may diminish with increasing severity of the disease. This apparent “professional subterfuge” undermines the health role in continuing care.

CCC believes that indicators relating to risk and quality of life should be included.

As above, the issue of perverse incentives arises. Care provider members of CCC are rightly concerned that they should be rewarded for achievement. If the result of good care is an improvement in the stability of a resident’s condition funding would be lost on reassessment.

CCC is concerned about how the indicators would trigger reassessment. There can be too much reassessment, with consequent cost and diversion of resources, not to mention distress to resident and family.

CCC is also concerned that there is a lack of consistency between the review of state benefits or funding granted to older and younger people, with underlying ageism. Whereas a younger incapacitated person is motivated to present themselves as “sick”, older people are often either pathetically grateful for assistance or ashamed to claim, or admit they need, support.

CCC notes, and greatly welcomes, the clarity of intent in government policy statements regarding the maintenance of dignity and a non-ageist approach to service delivery. However, the stated intent is in contrast with the apparent confusion in the proposed Framework for continuing care.

5. Do you have any views on the statements used to describe the key indicators?

As above.

6. Assessors will determine whether a primary health need is established by looking at the key indicators in terms of eleven generic ‘care domains’:

- a. **Behaviour**
- b. **Cognitive Impairment**
- c. **Communication**
- d. **Mobility**
- e. **Nutrition**
- f. **Continence**
- g. **Skin (including tissue viability)**
- h. **Breathing**
- i. **Drug Therapies and Medication**
- j. **Psychological/Emotional Needs**
- k. **Seizures/Altered States of Consciousness**

Bearing in mind that professional judgment is paramount and assessors can add to/override these on a case-by-case basis, are these the right core areas of need to assess?

No evidence base has been given to support the prioritisation of the decision support tool. CCC has serious concerns about the validity of assessments using this instrument. It is important that assessments are open to challenge, but insufficiently defined categories can only lead to what was described during a CCC internal consultation meeting as “a garden of Eden for lawyers”.

There would appear to be a conflict between these domains, which are fundamentally clinically-based, ie based on diagnosis, and the statement that the National Framework sets out to assess individuals on the basis of their need for care.

CCC strongly believes that it would be wrong to attempt to construct a definitive list. That said, the domains should include the place of care and the risk to the resident of being moved.

CCC contends that the process should be linked to the Single Assessment Process.

We are confused by the terminology employed above. If the indicators can be overruled, they must be guidance notes rather than key indicators. The basis on which they could be overruled is also not clear, nor is the frequency or likelihood of their being overruled. We again raise the question of how the performance of the assessors would be monitored.

7. What are your views on the process shown in the Assessment Framework? What are the potential implementation issues?

Quite simply – there are too many assessments. People do not want to be subject to multiple assessments. This view is held strongly by CCC members.

Assessment does not of itself provide care management, yet it should provide the starting point for good care or case management - an important function in determining care outcomes. Whatever the job title or professional background of the individual allocated the role of “seeing the person through the care system”, that function should be identified and made explicit. The function should be linked to the outcomes for the service user.

8. Do you agree with the concept of a national screening tool to help promote proportionate and appropriate assessments and to direct resources where they are most needed?

CCC’s long-standing position is that CCC recommends the adoption of a single national assessment instrument to ensure equity of access to appropriate levels of care and support. This, accompanied by transparency in decision-taking and a system of review and appeal, would offer both professionals and consumers a better opportunity to understand and work with the system.

In answer to the specific question above, CCC wholeheartedly agrees that there should be a national assessment tool – a coherent national assessment instrument that will trigger eligibility for care and care funding rather than ‘exception screening’.

If responsibility is devolved to PCTs, a national assessment tool will be particularly important.

CCC has long advocated the use of a common assessment tool, which will not only bring clarity and consistency to assessment but provide the basis for care planning – and, crucially, if additional funding is to be brought into the care system, be capable of being used by long-term care insurance or other additional funding methods.

Used as part of routine reassessment, the tool should be capable of triggering eligibility for care and care funding.

It is critical that the performance of the tool is monitored, with regional and national monitoring and including peer audit. Monitoring is essential to instil public confidence in the tool and, ultimately, the system.

9. What are your views on the concept of the national Decision-Support Tool to promote greater clarity and consistency in decision-making nationally.

We agree with the principle of consistent assessment nationally but the Decision-Support Tool does not appear to have evidential support. We therefore have very serious misgivings about the tool in its present form.

It is important that there is a mechanism to review how well the system is working. Quality control systems need to be in place, especially as PCTs are becoming larger. Benchmarking, published performance reports and the use of “Mystery shopper” case histories to determine the consistency of application should all be considered.

10. Do you think that the care planning process is the best place to establish whether an individual requires care from a registered nurse? What are the alternative processes for determining eligibility for NHS-funded Nursing Care?

All entrants into care, including those who are 'self-funders' should have access to a care assessment and there should be an agreed process for assessment. People in care homes without nursing should have the right of access to primary health care.

Care planning is a consequence of assessment. CCC contends that eligibility for NHS funding should not necessarily be linked to care from a registered nurse. For instance, medication management could be supervised by a pharmacist. Nutrition is another specialist area which can make a great difference to outcomes but in which the professional input may not necessarily be nursing input.

We reiterate our recommendation of the adoption of a single national assessment instrument to ensure equity of access to appropriate levels of care and support.

11. What are your views on the principle of removing the banding system for payments of NHS-funded Nursing Care?

CCC welcomes the proposal to remove the banding system, which we take to be a pragmatic decision and testimony to the failure of the present system. However, without an understanding of whether there will be proportionate national eligibility criteria for nursing support we have real reservations. What is required is a root and branch review of funding, taking into account the work undertaken by, and findings of, the Wanless Social Care Review and the Joseph Rowntree Foundation's Paying for Long-term Care programme.

CCC's preference is for a graded, escalating system that determines eligibility for whatever care is needed.

Whatever the features of a replacement system, the management of transition is crucial. There should be preserved rights – as a matter of principle – for those assessed within the present bands. We urge introduction of a new system only after properly-assessed pilot schemes.

When CCC members met to discuss the proposals, concerns were expressed about some specific points:

- What would happen to those receiving more than £97?
- Will there be banding by another name?
- Would the £97 be seen not as an average but as a ceiling?
- Would there be any perverse incentives?
- Guidance appears to be somewhat loose.
- Will funding be ring-fenced?
- What are the implications for individual budgets and direct payments?

Members are concerned about the adequacy of the level of funding proposed for the new single band.

12. What are your views on the following documents?

- a. 'Core Values and Principles'**
- b. Public Information Leaflet**
- c. Consultation Presentation**
- d. Partial Regulatory Impact Assessment**

The documents perpetuate the misconceived premise on which the funding of care is based. The basic premise is fundamentally flawed.

13. Any other comments on the issues raised by the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care?

The question of choice has not been raised: how a care home is chosen when the care is funded by the NHS. No choice direction applies in this case, as the Choice of Accommodation Directions do not apply to people fully funded by the NHS. For example, a resident in a residential care setting may be eligible for fully funded care. Could this enable high level nursing care to be provided in residential care or does it imply a move to a nursing home? CCC also believes that top-up payments should be permitted allowing individuals to choose more expensive care homes or options but with an ongoing responsibility for meeting the differential of that from the recommended option that can be funded from the public purse.

The principle of contestability needs to be included.

CCC, September 2006