

## Briefing Document

**An evaluation of the proposed National Framework Document for NHS Continuing Healthcare and NHS-Funded Nursing Care in England, issued for Consultation by the Department of Health on the 19<sup>th</sup> June 2006 (the Consultation period closes on the 22 September 2006).**

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### Summary

- The Consultation document fails the *Coughlan* test, in that Miss Coughlan would not qualify for NHS Continuing Care Funding under the new regime.
- The proposed National Framework Document fails to address almost all the problems that have been identified with the current NHS Continuing Care arrangements. It seeks to patch up a system that has been roundly condemned by persisting with criteria that are not *Coughlan*-compliant and have been rejected as opaque, unfair, inaccessible and at times incomprehensible.
- The new scheme is unlikely to result in many more people being identified or supported by the NHS to seek Continuing Care Funding
- The new scheme contains no concrete measures to address the severe delays that commonly occur in assessing those potentially entitled to Continuing Care Funding.
- The creation of a single national criteria for NHS Continuing Care is welcome, but the devolution of responsibility for the process to PCTs is in practice likely to worsen the local variations in entitlement to Continuing Care support.
- The absence in the new scheme of a quick, independent and robust review process (available for both patients and social services) is a major failing.
- The assessment process detailed in the draft Decision-Support Tool sets the bar for eligibility to NHS Continuing Care Funding at unlawfully high level.
- The proposed scheme makes no satisfactory arrangements to address the ‘entrenched mentality of ineligibility’ prevalent amongst NHS and social services staff.
- The Consultation document fails to address the continuing organisational reality for PCTs – namely that there are no organisational benefits for them to be gained by increasing the number of patients eligible for NHS Continuing Care Funding.

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## Preliminary notes

In this briefing paper, the following terms / abbreviations are used.

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| Consultation document    | this means the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care in England: Consultation Document issued by the Department of Health <sup>2</sup> |
| <i>Coughlan</i>          | this is a reference to the Court of Appeal judgment in <i>R v. North and East Devon health authority ex p Coughlan</i> <sup>3</sup>   |
| Decision-Support Tool    | this means the draft version of the National Framework for NHS Continuing Healthcare in England Decision-Support Tool <sup>4</sup>  |
| <i>Grogan</i>            | this is a reference to the High Court judgment in <i>R (Grogan) v. Bexley NHS Care Trust and others</i> (2006) <sup>5</sup>   |
| <i>Leeds</i> complaint   | this refers to a complaint considered by the Health Services Commissioner – outlined in Table 2 at the end of this briefing document.   |
| <i>NHSCC</i>             | this means NHS Continuing Care  |
| <i>Pointon</i> complaint | this refers to a complaint considered by the Health Services Commissioner – outlined in Table 2 at the end of this briefing document.   |
| <i>Wigan</i> complaint   | this refers to a complaint considered by the Health Services Commissioner – outlined in Table 2 at the end of this briefing document.   |

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<sup>2</sup> Accessible at <http://www.dh.gov.uk/assetRoot/04/13/63/88/04136388.pdf>

<sup>3</sup> *R v. North and East Devon health authority ex p Coughlan* [2000] 3 All ER 850 accessible at <http://www.bailii.org/cgi-bin/markup.cgi?doc=/ew/cases/EWCA/Civ/1999/1870.html>

<sup>4</sup> Accessible at <http://www.dh.gov.uk/assetRoot/04/13/63/93/04136393.rtf>

<sup>5</sup> [2006] EWHC 44 (Admin) 25/01/2006 accessible at <http://www.bailii.org/cgi-bin/markup.cgi?doc=/ew/cases/EWHC/Admin/2006/44.html>

## Introduction

This briefing document has been prepared in response to the draft guidance on entitlement to *NHS Continuing Care (NHSCC)* funding issued by the Department of Health for consultation in June 2006. The Government has undertaken this process because the previous (2001) guidance has almost universally been deemed defective: in the words of the Regulatory Impact Assessment accompanying the Consultation document<sup>6</sup> ‘critical reports, negative media coverage and the outcome of legal cases’. These criticisms have been in unusually robust language and have come from a broad spectrum of informed sources, including the courts, the NHS Ombudsman, the Health Select Committee, patient groups, practitioners, academic commentators, and the media (notably the ‘The National Homes Swindle’ Panorama programme of March 2006). The proposed new scheme will only apply in England. Separate (and equally defective) arrangements apply in Wales.

The Government claims that the revised guidelines are *Coughlan* compliant. One needs to be cautious about accepting this at face value given that this is the same claim made by the same Government in relation to the 2001 guidance; the same Government that, following the *Coughlan* judgment, issued advice to health authorities that ‘could justifiably have been read as a mandate to do the bare minimum’<sup>7</sup>.

The simplest test as to whether the new guidelines accord with the law – ie are *Coughlan* compliant – is to gauge whether in practice they will result in a significant lowering of the bar: whether they will remove the ‘gap’ identified by Charles J in *Grogan*, between the current (2001) guidelines which require patients to establish a very high level of health care need to qualify for *NHSCC*, and the *Coughlan* test that creates an altogether lower threshold. One can gauge whether the new guidelines pass this test by running the ‘*Coughlan* experiment’ ie by asking whether Miss Coughlan (or indeed any of the other patients listed Table 2 at the end of this paper) would qualify for *NHSCC* under the new guidelines. These patients are a good sample since none of them are ‘borderline’ and some of them have been used as benchmarks by the NHS Ombudsman (for instance *Coughlan*<sup>8</sup>) and the Government (for instance the *Leeds* complaint<sup>9</sup>).

I have applied the Decision-Support Tool criteria to the four cases listed in Table 2 and the results are detailed in Table 1 below. I have discussed these results with a number of other lawyers with expertise in this field, whose only criticism has been that I may have been overgenerous in my assessments.

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<sup>6</sup> at para 12, accessible at <http://www.dh.gov.uk/assetRoot/04/13/63/90/04136390.pdf>

<sup>7</sup> The Health Service Commissioner noted in her Second Report for Session 2002-2003 *NHS funding for long term care*; Stationery Office. HC 399 (at para 21) ‘My enquiries so far have revealed one letter (in case E.814/00-01) sent out from a regional office of the Department of Health to health authorities following the 1999 guidance, which could justifiably have been read as a mandate to do the bare minimum’.

<sup>8</sup> See for instance the comments of the Health Service Commissioner in her 2003 report concerning Wigan and Bolton Health Authority and Bolton Hospitals NHS Trust Case No. E.420/00-01 [Second Report for Session 2002-2003 *NHS funding for long term care*; Stationery Office. HC 399.

<sup>9</sup> Department of Health Press Release of 4.11.94 and the Department of Health in its guidance EL (96)8 at para 16.

**TABLE 1**

|                   | Priority | Severe | High | Medium | Low | None |
|-------------------|----------|--------|------|--------|-----|------|
| The Leeds patient | 0        | 2      | 1    | 3      | 1   | 4    |
| Miss Coughlan     | 0        | 1      | 0    | 2      | 0   | 8    |
| The Wigan patient | 0        | 2      | 2    | 3      | 1   | 3    |
| Mr Pointon        | 0        | 1      | 2    | 2      | 1   | 5    |

Paragraph 19 of the Decision-Support Tool advises that entitlement to *NHSCC* requires either:

- A **priority** level need in any one of the four domains which carry this level.
- A total of two incidences of identified **severe** level needs across all care domains.
- A number of domains with **high** and/or **moderate** level needs, which, in the judgment of the assessor, demonstrates an overall primary health need following the principles above.

The new guidelines therefore fail the *Coughlan* experiment – since Miss Coughlan does not qualify for *NHSCC* under the revised scheme. In this regard it is important to emphasise that her nursing care needs have been held to be ‘well outside the limits of what could be lawfully provided by a local authority’<sup>10</sup>. Indeed none of the patient’s qualify on the first ground of the Decision-Support Tool (para 19) since none get a ‘Priority’ score. The Wigan patient only just creeps into the second ground (two ‘severe’ needs): this is a case where the Health Service Commissioner held that (in effect) only a PCT that had taken leave of its senses could decide there was no entitlement to *NHSCC*<sup>11</sup>.

Of course it could be said that there is nothing wrong with the descriptors of the various levels within the Care Domains in the Decision-Support Tool, but that the problem lies with my assessment. This in itself is no argument: if the descriptors are capable of being misunderstood by lawyers experienced in this field of law, they are no less likely to be misunderstood by practitioners in the field – especially practitioners inured in the previous regime where the bar to qualification was placed at an equally unrealistic level.

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<sup>10</sup> *R (Grogan) v. Bexley NHS Care Trust and others* [2006] EWHC 44 (Admin) 25/01/2006 at para 61.

<sup>11</sup> The NHS Ombudsman stated in this case ‘*I cannot see that any authority could reasonably conclude*’ – essentially a version of the test in *Associated Provincial Picture Houses v Wednesbury Corporation* [1948] 1 KB 223 (ie that no reasonable public body could have reached such a decision). In *R v SS Environment ex p Nottinghamshire CC* [1986] AC 240, HL at 247 the House of Lords suggested that the *Wednesbury* test was amenable to a more succinct expression, namely ‘have taken leave of [its] senses’.

## Present problems

A more detailed evaluation of the new proposals requires, first the identification of the problems within the existing scheme and, second consideration of the new arrangements to assess the likelihood of them proving more effective in addressing these shortcomings.

These present shortcomings include:

- ***Unlawful / inappropriate criteria***  
The use of non-*Coughlan* compliant criteria; the use of inappropriately demanding criteria; the use of ambiguous and incomprehensible language; the use of terminology that does not correspond with the wording used in the statutes and case law
- ***Obstruction and delay***  
The failure of the NHS to identify and empower people who may be entitled to *NHSCC* and the severe delays that commonly occur in assessing those identified as potentially entitled to *NHSCC*.
- ***Local variations in entitlement and lack of central scrutiny***  
The significant local variations in entitlement to *NHSCC* and the failure of the Department of Health and the Strategic Health Authorities (SHA's) to police adequately the day to day *NHSCC* decision making by local health bodies.
- ***The lack of a quick, fair, and robust review process***  
The lack of rapid and robust arbitration / binding review procedures – available not merely for aggrieved patients and their carers but also for local authority social services.
- ***Inappropriate assessment tools***  
The use by local health bodies of inappropriate assessment tools to establish *NHSCC* eligibility – as, for instance, was the case in the *Pointon* complaint.
- ***The entrenched mentality of ineligibility***  
The entrenched view of many NHS and social services staff that in practice eligibility for *NHSCC* requires very severe ill health allied to an unstable condition.
- ***The organisational imperative.***  
That from the perspective of local NHS bodies, there are no organisational benefits to be gained by increasing the number of patients eligible for *NHSCC* or by improving the speed and fairness of the decision making process: indeed the reverse is the case.

## Evaluation

### *Unlawful / inappropriate criteria*

An assessment of whether the criteria are fit for purpose raises two separate questions. The first, which is fundamental, concerns their legality and the second concerns the more general question of their appropriateness.

#### 1. Legality

##### (a) **The misrepresentation of *Coughlan***

It is not clear from the current consultation whether the final guidance will commence with an accurate and comprehensible statement concerning the findings by the Court of Appeal in *Coughlan*. This must however be a *sine qua non*. The consultation draft does not cite verbatim the key part of the *Coughlan* judgment (ie para 30(e)): it must. At para 30(e) the Court made a very simple point, namely that a person could not be supported by social services if either the quality of the care or its quantity was outside that which a local authority could provide. It is essential that there be a clear statement in the guidance that if either the quantity **or** the quality thresholds are crossed the local authority cannot lawfully fund the care. The current guidance however upends this proposition or at the very least severely confuses it by suggesting that there is an '**and**' between the quality and quantity tests (see for instance para 14 and the definition of intensity at Figure 1 page 9).

##### (b) **The fundamental misconception**

The Consultation document places at its centre the proposition that entitlement to *NHSCC* support is based upon the test of whether a person's 'primary need is a health need' (see eg para 13). This approach is not the one adopted by the Court of Appeal in *Coughlan*. In that case the court referred to this approach on only one occasion (para 31) where it noted that the 'Secretary of State accepts that, where the primary need is a health need, then the responsibility is that of the NHS, even when the individual has been placed in a home by a local authority'. The court however immediately went on to suggest that such an approach presented difficulties and ultimately it opted for an altogether different test – namely one that sprang from s21(8) National Assistance Act 1948. In effect, it asked an entirely different question. Not "what is the NHS's responsibility?" but "what is the limit of social services' responsibility?"

The 'primary health need' test is therefore not only inappropriate (in that it is not justified by the case law) it wrongly suggests that the NHS is the arbiter of the *NHSCC* determination and is, in many respects, meaningless. Considering these questions separately:

*The arbiter of NHSCC entitlement.*

The ‘primary health need’ test directs attention to the NHS. It asks a question that common sense would suggest is for health care professionals to answer: they are after all the experts on what is a health care need. Accordingly once this inappropriate test has been accepted, it follows that the ‘NHS should make the decision on responsibility’ for *NHSCC* – and this is exactly what is stated at para 33 of the Consultation document (albeit ‘working in collaboration with Social Services’). This however turns on its head, the judgments in *Coughlan* and *Grogan*. In both these cases the key question was whether the care required went beyond that which social services could lawfully provide – as delimited by s21(8) of the 1948 Act. If one therefore adopts the ‘limits of social care’ test applied by the courts, one comes to a very different conclusion – namely that the social services authority makes the decision on *NHSCC* entitlement (by default). It may of course be argued that this is unsatisfactory since there would be a financial incentive on social services to find *NHSCC* entitlement, but then the converse is equally true, namely that it is in the NHS’s interests to find no entitlement. An appropriate resolution would require therefore that it be a joint decision with immediate access to independent and binding arbitration if the two cannot agree.

*The primary health need test as a virtually a meaningless criterion*

The primary health need test is not only the wrong test, it is also difficult to understand what it actually means: it is not self evident. One, for instance would have thought that any person placed in a nursing home was there because their primary need was a health need (otherwise they could remain in their own home – or a residential care home with the district nurse making periodic visits). One assumes that the proposal is not that everyone in a nursing home should qualify for *NHSCC* support – and so exactly what is meant by the primary health need?

The Consultation document suggests, by a circular route, that the meaning of the phrase is that a person has a primary health need if their health care needs do not fall within the *Coughlan* quality / quantity criteria (see para 14). If this be so, then why does the guidance not use this criterion – ie the ‘limits to social services responsibility’? This approach has many material benefits. For instance, such a test immediately raises a question – namely ‘what are the limits to social services’ responsibilities?’ And the answer takes the discourse directly back to the Court of Appeal’s carefully phrased quality / quantity criteria. However if one asks ‘what is a primary health care need?’ the answer (as given by the Consultation document) is a number of ambiguous and frequently conflicting concepts of questionable legality, such as the nature, complexity, intensity and unpredictability of the condition.

The concepts applied in the guidance should as closely as possible follow the approach of the courts – they should not seek to construct an entirely separate architecture of entitlement. Such an approach has led to judicial censure of the

1995 guidance in *Coughlan* and of the 2001 guidance in *Grogan* and is almost certain to lead to further litigation.

## 2. **Inappropriate terminology**

The proposed guidance uses inappropriate terminology and makes reference to a number of criteria that do not correspond with the wording used in the statutes and case law.

### (a) **Inappropriately demanding criteria**

The failure of all four of the benchmark cases listed in Table 2 to record a 'priority' score (see above) is evidence (if evidence were needed) that the priority band is unrealistically demanding. There is a serious problem with creating a first category that is so high (ie that requires patients to be so very profoundly ill). The danger is that by implication the second category will always be considered 'less clear-cut'; ie for patients who are less obviously entitled to support. This problem is exacerbated because in the second category multiple needs are required – suggesting that no one need alone (if merely 'severe') is sufficient to qualify for entitlement. This means, for instance, that severe incontinence difficulties or feeding difficulties, or skin ulcers / wounds, can never be sufficient alone to qualify a person for *NHSCC*. Previous guidance (EL (96)8)) has been (rightly) critical of continuing care statements which placed such an emphasis on the need for people to meet multiple criteria in order to qualify for *NHSCC*.

### (b) **Ambiguous / incomprehensible criteria**

#### (i) *Nature, complexity, intensity and unpredictability*

No useful purpose is served by retaining the above four descriptors. Indeed to elevate these to 'key indicators' (page 9 Figure 1) seriously undermines the effectiveness of the proposed guidance. The reasons for this includes:

1. The Court of Appeal, in *Coughlan* considered that the key criteria were simply the 'quality and quantity' of the care provided. In order to assess whether either of these two factors had exceeded the s21(8) boundary, the court provided the '*merely incidental or ancillary*' test for quantity but only very general advice in relation to the quality of care. In terms of assessing the quality of care, the 'Care Domains' in the Decision-Support Tool make up for this short-fall. In order that the process be as simple as possible, the guidance should direct assessors to the 'Care Domains' in the Decision-Support Tool without requiring preliminary consideration of the 'nature, complexity, intensity and unpredictability' indicators. They unnecessarily complicate and indeed confuse the process. They appear to create an intermediate (and daunting) hurdle. The explanations in Figure 1 (page 9

Consultation Document) for instance suggest that a condition cannot be deemed ‘unpredictable’ or ‘complex’ unless it is extremely serious.

2. The indicators are elusive and overlapping; they service no clear purpose and are very likely to confuse. It is difficult, for instance, to understand what consideration of the ‘nature’ of a condition adds – especially when the explanation directs attention back to the ‘quality / quantity’ division. The explanation provided in the Consultation document (page 9 Figure 1) suggests that ‘nature’ includes the type of intervention but then suggests that the ‘intensity also includes the ‘quality and quantity of the care provided’. If this is not duplication, it is an extremely esoteric difference that is difficult to justify.
3. All previous guidance has placed an ‘or’ between the four criteria. In the draft consultation, ‘or’ is not only missing – at times the word ‘and’ appears in substitution (see eg para 150. This again suggests that patients will have to satisfy multiple criteria. Previous guidance issued by the Department of Health (EL (96)8)) was critical of continuing care statements which, rather than being sensitive to the complexity *or* intensity *or* unpredictability of a person’s needs, placed too much emphasis on the need for people to meet multiple criteria for NHS-funded care.

(ii) Specialist.

Not inconsiderable concern has been expressed over the repeated use in continuing health care statements of undefined terms such as ‘specialist’. EL (96)8 at para 16, for instance, criticised statements which placed an ‘over-reliance on the needs of a patient for specialist medical supervision in determining eligibility for continuing in-patient care’ and specifically referred to the fact that this was not considered by the NHS Ombudsman in the *Leeds* case as an acceptable basis for withdrawing NHS support.

In *Coughlan* the Court considered that in many cases the concept of ‘specialist’ was devoid of meaning, was unhelpful, ‘elusive’ and ‘idiosyncratic’ (at paras 13 and 41).

Whilst the main Consultation document avoids reference to ‘specialist’ in terms of the care required in order to access *NHSCC*, the Decision-Support Tool makes many references to such a requirement including at least 10 occasions when used in the context of determining eligibility. By way of example, in order to be adjudged ‘high’ or ‘priority’ in the Behaviour Care Domain there is a requirement for specialist involvement. This, notwithstanding that it was not deemed essential in the *Pointon* determination. Likewise with the Psychological/Emotional Needs Care Domain a high grading requires (amongst other things) specialist support and intervention and for the Seizures or Altered States of Consciousness

Care Domain a high grading requires intervention of ‘specially trained carer’ or qualified nurse.

The requirement for an input to be by a specialist has an additional and insidious aspect. Potentially it suggests that it is not the existence of a need but of formal acceptance by a specialist of a condition that is a precondition to eligibility. Such a requirement has the potential to erode the principle that diagnosis is not the determinant of eligibility for *NHSCC* support.

(iii) Professional judgment is paramount

The above mentioned danger, that may result from an over reliance on the word ‘specialist’ in the Decision-Support Tool is increased by the repeated use of the phrase ‘professional judgment is paramount’. This appears once in the consultation Document, twice in the Decision-Support Tool and twice in the Core Values and Principles Document. The phrase bears many meanings. It might mean that in every assessment an opinion be obtained from a professional before a decision on entitlement is made. The unexplained use of the word ‘paramount’ however makes this explanation unlikely. The suggestion appears to be that the view of a professional is determinative. However it is not clear why a professional view should be so important in the case of a patient entitled to *NHSCC* on the ‘quantity’ ground. What in any event is meant by a ‘professional’ – does this mean an NHS professional and does this person have to belong to a professional body?

The phrase should either not be used or its meaning be spelt out with clarity and care.

### ***Obstruction and delay***

Nothing in the Consultation documents suggests that the severe delay (and outright refusals to assess) that characterise the current system (and the review process) are likely to change. The document contains nothing that suggests that the pressure to discharge patients from hospital as soon as is possible is likely to change. It contains nothing to indicate that the demand for hospital beds and the delayed discharge fining procedures will continue to do anything other than maintain the present organisational incentive to pay little of no attention to patients’ *NHSCC* entitlements.

A particular group of patients for whom the absence of any expediting provisions is likely to cause severe distress is those who appear to be likely to die in the near future. Considerable dissatisfaction has been expressed concerning the patchy nature of health body acceptance of responsibility for such patients<sup>12</sup> and the Consultation papers do not provide any concrete mechanisms by which these problems will be overcome

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<sup>12</sup> See for instance House of Commons Health Committee Fourth Report of Session 2003–04 on Palliative Care, Volume HC 454-I.

The volume of complaints concerning the failure of health bodies to accept responsibility for *NHSCC* funding and the success of so many of these complaints is strong evidence that the system has failed large numbers of people. Many of these have come into contact with health and social care professionals who have either ignored or inappropriately rejected their entitlement to *NHSCC* support.

The Consultation document addresses this problem in somewhat convoluted language that appears to state (para 34) that assessment of entitlement to *NHSCC* funding should take place either (1) when discharge planning commences; or if the person is living in the community (presumably including a care home) when either (2) a ‘health care episode occurs’ or (3) if nurses (presumably district nurses) are involved ‘routinely through the involvement of nurses in regular assessments of nursing needs’.

This is inadequate and, in the absence of further mandatory guidance / directions is likely to be as ineffective as the current process – the reasons for this being:

1. The new guidance is vague and is merely a restatement of what should already occur.
2. Patients are not being properly assessed as part of hospital discharge planning. Discharge planning is dominated by delayed discharge targets. Although the NHS should not serve a discharge notice under section 2 of the Community Care (Delayed Discharge) Act 2003 until it is decided that a patient is not entitled to *NHSCC*<sup>13</sup> – frequently this is either treated as a formality (ie none are assessed as entitled) or the notice unlawfully states that no decision on *NHSCC* entitlement has been made. There is no reason to believe that this practice will cease – given the continuing dominance of NHS waiting list targets.
3. Reliance on primary care staff (GP’s and district nurses) to assess entitlement to *NHSCC* is unrealistic. The entrenched mentality amongst front line NHS staff is that almost no-one is entitled to *NHSCC*. In the absence of very major re-education / awareness raising of such personnel, the belief of non-entitlement will persist (see below).

Assessment procedures will only improve if:

1. There is a duty to assess which is triggered, not on a request, but on an ‘appearance of need’ (ie in similar terms to the s47(1) NHS Community Care Act 1990 duty);
2. In relation to patients awaiting hospital discharge, the assessment is undertaken jointly by the relevant NHS and social services staff and that the delayed discharge procedures are not activated until these bodies have reached agreement (or the arbitration / review procedure has concluded the question – eg if the patient or the social services authority have challenged an NHS non-entitlement assessment);
3. In relation to people not in hospitals (ie in care homes or in ‘in the community’) there must be:
  - a) a positive obligation on NHS, social services and care home staff to advise them of their rights;

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<sup>13</sup> The Delayed Discharge (Continuing Care) Directions 2003 dir 2.

- b) a positive obligation to undertake *NHSCC* assessments if ‘it appears’ to health or social services staff that the person may be entitled. In this context, it should be observed that there is a troubling lack of reference to the Single Assessment Process in the Consultation document;
  - c) A positive obligation on social services staff to consider entitlement to *NHSCC* support when undertaking a community care or Children Act assessment.
4. The extent to which the NHS do inform patients of their entitlement to *NHSCC* support and the extent to which meaningful assessments (as opposed to tokenistic assessments) of entitlement should be the subject of robust auditing by the Healthcare Commission – with dissuasive penalties being imposed on trusts that fail to properly discharge their obligations in this respect.
  5. That for terminally ill patients there is a dedicated and expedited procedure for assessment and review (in the case of disagreements).

### ***Local variations in entitlement and lack of central scrutiny***

The creation of a single set of criteria for all health bodies in England is to be welcomed. Unfortunately, however the Framework and the proposed Decision-Support Tool are so defective (for the reasons outlined in this paper) that the new scheme has the potential to materially erode the existing rights of many patients under the present very imperfect local criteria.

The proposal is that responsibility for decision making under the new scheme will devolve to PCTs. Given the failure of the Department of Health to adequately scrutinise the Continuing Care Statements issued by the Strategic Health Authorities<sup>14</sup> and the failure of these authorities to properly police the day to day decision making by their local health bodies<sup>15</sup> it is likely that the new arrangements will lead to a significant deterioration in what is already a very poor system.

### ***The lack of a quick, fair and robust review process***

The ‘Core Values and Principles’ document accompanying the consultation states that the existing review procedures will remain. The frustration of patients, carers and social services authorities with these arrangements and the volume of complaints before the NHS Ombudsman is testimony to the inadequacy of the current scheme. It contains no truly independent stage, is slow, Kafkaesque in its processes and has a strong tendency to uphold the NHS decision. Time and time again patients are dying before any decision is reached; time and time again patients and their carers are abandoning the process because it is too complicated and traumatic.

There is, as detailed above, no legal justification for the process being NHS led. The absence of a truly independent element is a serious failing – especially as very large sums

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<sup>14</sup> For instance the Bexley NHS Care Trust statement the subject of the *Grogan* proceedings.

<sup>15</sup> Evidenced by the very large number of complaints before the NHS Ombudsman.

of money may be in issue and the requirements of article 6 of the European Convention on Human Rights will be engaged.

The new arrangements must provide for a rapid and robust arbitration / binding review procedure. This scheme (or a parallel scheme) must also be available for NHS / social services disputes. It should not be forgotten, that social services are seriously financially disadvantaged by the current arrangements. The *Grogan* judgment, in effect, held that (at the very least) over 20,000 people in England<sup>16</sup> are being inappropriately charged for their nursing home accommodation. This means that in each English social services authority area on average at least 130 self funding or local authority funded residents should in fact be funded by the NHS. If only half of these are funded by local authorities<sup>17</sup> it could amount to inappropriate council expenditure considerably in excess of £1.75 million per annum.

### *Inappropriate assessment tools*

Even if the criteria required to achieve a high score on Care Domains in the Decision-Support Tool are placed at realistic levels – ie revised downwards – the assessment tool will still be inadequate. There are two major reasons for this. The first concerns the actual Care Domains approach and the second relates to the short comings with any such assessment tool.

1. The problem with the Care Domains approach, is that it has the effect of obscuring the *Coughlan* ‘quantity’ category. Indeed the absence of detailed analysis of the quantity category is marked and extremely troubling. The Court of Appeal in *Coughlan* placed equal emphasis on the quantity and quality categories, but the Decision-Support Tool very heavily concentrates upon the quality criterion. This bias must be redressed.
2. Valuable as (properly constructed) assessment tools may be, sole reliance upon them creates a serious problem. This is that by requiring practitioners to focus on the micro level, the process can obscure the macro reality – that the wood is not seen for the trees. Although many such tools pay lip service to the need for practitioners also to ‘stand back’ and look at the larger picture – all too often this is tokenistic (in the guidance) and ignored by practitioners. Tools of this nature require, therefore a secondary ‘cross-checking’ procedure; a formal requirement that the assessor ‘stand back’ and look at the patient ‘in the round’. In the present context, an appropriate process would include the use in of worked examples in the Decision-Support Tool showing how and why a series of bench marks / case

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<sup>16</sup> The judgment found that ‘registered nursing care falling within the high band (and perhaps the medium bands)’ was above the *NHSCC* threshold. If one considers only those persons on the high band (and therefore ignores those on the medium band and those patients living in the community) then: it appears that there were about 15 – 20,000 people in high band RNCC at the time of the *Grogan* decision: see Henwood, M (2006) *Self-funding of long-term care and potential for injustice* (Background Paper prepared for BBC Panorama) accessible at [http://news.bbc.co.uk/1/shared/bsp/hi/pdfs/05\\_03\\_06\\_melaniehenwood.pdf](http://news.bbc.co.uk/1/shared/bsp/hi/pdfs/05_03_06_melaniehenwood.pdf)

<sup>17</sup> The Royal Commission on Long Term Care (1999) *With Respect to Old Age* put the figure at over 70% (see Table 2.1 p 9).

studies (eg of Miss Coughlan, the Leeds patient, the Wigan patient and Mr Pointon) would qualify for *NHSCC* under the new regime.

### ***The entrenched mentality***

The entrenched view of many NHS and social services staff is that qualification for *NHSCC* requires very severe ill health allied with an unstable condition. For 10 years the Department of Health guidance has encouraged this perception amongst front line staff – such that people as ill as the patient in the *Wigan* complaint and Mr Pointon have been refused *NHSCC*.

As noted above, the Department of Health in 1999 indicated that the *Coughlan* judgment did not require significant amendment to the then criteria. Accordingly health bodies have been inappropriately encouraged by the Department of Health for over a decade to believe that access to *NHSCC* support requires a very high threshold to be crossed. Unless there is a very clear statement in the new Framework that this was wrong, that the new scheme is significantly different and that it is expected that many more people will qualify, the existing mindset amongst health and social care staff will persist.

Regrettably there is no such recognition in the proposed guidance or indeed in the Regulatory Impact Assessment (RIA) accompanying the Consultation document<sup>18</sup>. The RIA does not accept that the 2001 guidelines were seriously defective: it merely states (at para 23) that ‘the current situation has resulted in criticism, adverse media coverage and increases the potential for disputes’.

### ***The organisational imperative.***

In organisational terms it is not in the NHS interest to seek out patients who are entitled to *NHSCC* funding. Devoting resources to this merely increases PCT expenditure and slows down hospital discharge. There are no Government targets that would encourage trusts to devote funds to this objective. In the absence of positive incentives or effective, and dissuasive sanctions the organisational imperative will ensure that any new *NHSCC* initiative becomes sidelined: that health bodies respond by doing the ‘bare minimum’.

The proposed guidelines contain no such incentives or sanctions.

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<sup>18</sup> Accessible at <http://www.dh.gov.uk/assetRoot/04/13/63/90/04136390.pdf>

**TABLE 2****Resume of patients involved in continuing care disputes*****Leeds Ombudsman Report Case No E.62/93-94 January 1994***

A man suffered a brain haemorrhage and was admitted to a neuro-surgical ward. ... He received surgery but did not fully recover. After 20 months in hospital he was in a stable condition but still required full time nursing care. His condition had reached the stage where active treatment was no longer required but that he was still in need of substantial nursing care, which could not be provided at home and which would continue to be need for the rest of his life (para 22 of report)

The importance of this assessment was emphasised in NHS guidance EL (96)8 which (at para 16) criticised continuing care statements which placed an ‘*over-reliance on the needs of a patient for specialist medical supervision in determining eligibility for continuing in-patient care*’ and specifically referred to the fact that this was not considered by the ombudsman in the Leeds case as an acceptable basis for withdrawing NHS support.’

***R v North and East Devon Health Authority ex p Coughlan***

Miss Coughlan was grievously injured in a road traffic accident in 1971. She is tetraplegic; doubly incontinent, requiring regular catheterisation; partially paralysed in the respiratory tract, with consequent difficulty in breathing; and subject not only to the attendant problems of immobility but to recurrent headaches caused by an associated neurological condition. (para 3 of judgment)

The court concluded at para 3

*The Secretary of State accepts that, where the primary need is a health need, then the responsibility is that of the NHS, even when the individual has been placed in a home by a local authority ... Here the needs of Miss Coughlan ... were primarily health needs for which the Health Authority is as a matter of law responsible*

***Wigan and Bolton Health Authority and Bolton Hospitals NHS Trust Case No. E.420/00-01*<sup>19</sup>**

Mrs N had suffered several strokes, as a result of which she had no speech or comprehension and was unable to swallow, requiring feeding by PEG tube (a tube which allows feeding directly into the stomach). Mrs N was being treated as an in-patient in the Trust’s stroke unit and was discharged to a nursing home (para 1 p 24)

Health Services Commissioner concluded (at para 30, p32)

*I cannot see that any authority could reasonably conclude that her need for nursing care was merely incidental or ancillary to the provision of accommodation or of a nature one could expect Social Services to provide (paragraph 15). It seems clear to me that she, like Miss Coughlan, needed services of a wholly different kind.*

***Complaint against Cambridgeshire Health Authority & PCT*** (the ‘Pointon’ case)<sup>20</sup> Mr P is severely disabled with dementia and unable to look after himself. His wife cared for him at home . She took a break one week in five but had to pay more than £400 for the substitute care assistant, because the NHS would not pay, because Mrs P was not a qualified nurse (and could not therefore be offering nursing care). It was held that the fact that Mr P was receiving (what was in effect) nursing care from his wife, did not mean he could not qualify for continuing health care; that the health bodies had failed to take into account his severe psychological problems and the special skills it takes to nurse someone with dementia; that the assessment tools used by the NHS were skewed in favour of physical and acute care; the fact that MR P needed care at home – rather than in a nursing care home was not material to the question of continuing health care responsibility.

<sup>19</sup> From the NHS Ombudsman’s Second Report for Session 2002-2003 *NHS funding for long term care*; Stationery Office. HC 399.

<sup>20</sup> Accessible on the NHS Ombudsman’s web site at [www.ombudsman.org.uk/hsc/document/pointon.pdf](http://www.ombudsman.org.uk/hsc/document/pointon.pdf)