


The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care

July 2009 (revised)



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The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care

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Contents

Executive Summary	1
The National Framework	3
Legal framework	6
Primary health need	9
Core values and principles	12
Eligibility consideration	18
Commissioning, care planning and provision	28
Access to other NHS-funded services	30
Links to other policies	33
Review	39
Dispute resolution	41
Governance	45
Annex A: Glossary	46
Annex B: The Coughlan judgment	50
Annex C: The Grogan judgment	52
Annex D: Determining the need for NHS-funded nursing care	54
Annex E: Independent review panel procedures	56

Executive Summary

- 1. The National Framework.** This revised framework sets out the principles and processes of the National Framework for NHS continuing healthcare and NHS-funded nursing care. Revised directions will be issued under the National Health Service Act 2006 and the Local Authority Social Services Act 1970 in relation to the National Framework.
- 2. Legal framework.** We set out the main responsibilities for the NHS and local authorities (LAs) that are in primary legislation, and explain the influence of key court cases. The *Coughlan* judgment examined the responsibilities of the NHS and LAs, particularly regarding the provision of nursing care. The *Grogan* judgment examined the interaction between NHS continuing healthcare and NHS-funded nursing care.
- 3. Primary health need.** We describe how the phrase a ‘primary health need’ has developed, and how this concept helps in determining when someone should receive NHS continuing healthcare.
- 4. Core values and principles.** We set out the main things to remember when assessing somebody and deciding whether they should receive NHS continuing healthcare. The individual, the effect their needs have on them, and the ways in which they would prefer to be supported should be kept at the heart of the process. Access to assessment, care provision and support should be fair, consistent and free from discrimination.
- 5. Eligibility consideration.** At the heart of the Framework is the process for deciding whether someone is eligible for NHS continuing healthcare or NHS-funded nursing care. Assessments should be carried out by a multidisciplinary team, in line with the ‘Core Values and Principles’ section, and should take account of other existing guidance.
- 6. Commissioning, care planning and provision.** The primary care trust should identify and arrange all services required to meet the needs of all individuals who qualify for NHS continuing healthcare and for the healthcare element of a joint care package. We set out the key principles in both circumstances.
- 7. Access to other NHS-funded services.** Those entitled to NHS continuing healthcare continue to be entitled to access to the full range of primary, community, secondary

and other health services. We also set out how joint packages of health and social care services should operate.

- 8. Links to other policies.** We point to other areas of law and policy that may be relevant to this Framework, especially areas concerning mental health, children's continuing care and personal health budgets.
- 9. Review.** Regular reviews should be carried out – the first no later than three months after the initial decision, and then at least once a year subsequently. Some people will need more frequent reviews. We describe this in more detail.
- 10. Dispute resolution.** We set out the processes to follow when there is a disagreement concerning an eligibility decision. Separate procedures are set out for disputes between the NHS and LAs, and for when an individual disagrees with a decision or with the process used to reach it. We also describe the other steps that may be taken if this does not provide a satisfactory solution or if an individual wants to complain separately using the relevant complaints procedure.
- 11. Governance.** Both primary care trusts and strategic health authorities have roles in overseeing the process. We explain this in the final section.

The National Framework

Summary

1. This revised guidance sets out the principles and processes of the National Framework for NHS continuing healthcare and NHS-funded nursing care. It concentrates mainly on the process for establishing eligibility for NHS continuing healthcare and the principles of care planning and dispute resolution relevant to that process, rather than specifying every detail of the planning of NHS continuing healthcare.

Revised directions will be issued under the National Health Service Act 2006 and the Local Authority Social Services Act 1970 in relation to the National Framework.

Actions

2. **Primary care trusts** (PCTs) should consider how the principles and processes in this revised guidance relate to what is currently in place, and should align their processes accordingly. They should also consider where NHS continuing healthcare responsibilities require clearer arrangements to be made with provider organisations, and should ensure that these are built into commissioning processes.
3. **Strategic health authorities** (SHAs) should help facilitate this process. There is a continuing requirement for SHAs to operate independent review panels. Revised guidance on the operation of panels is set out in this Framework. SHAs should also be mindful of their own responsibilities – and those of PCTs – as set out in the ‘Governance’ section below.
4. **Local authorities** (LAs) should consider this guidance and review whether their current practice fits with the responsibilities outlined below.
5. **NHS trusts** should consider the relevant sections of this guidance as they review their current discharge procedures.
6. **PCTs, NHS trusts and LAs** are encouraged to work together in a partnership approach when they review existing processes.
7. **PCTs, NHS trusts, LAs and SHAs** should comply with their responsibilities, as set out in this Framework and the revised directions to be issued under the National Health Service Act 2006 and the Local Authority Social Services Act 1970 in relation to the National Framework.

Background

8. 'Continuing care' means care provided over an extended period of time, to a person aged 18 or over, to meet physical or mental health needs that have arisen as a result of disability, accident or illness. 'NHS continuing healthcare' means a package of continuing care that is arranged and funded solely by the NHS. The actual services provided as part of that package should be seen in the wider context of best practice and service development for each client group. Eligibility for NHS continuing healthcare places no limits on the settings in which the package of support can be offered or on the type of service delivery.
9. An individual who needs 'continuing care' may require services from NHS bodies and/or from LAs. Both NHS bodies and LAs, therefore, have a responsibility to ensure that the assessment of eligibility for continuing care and its provision take place in a timely and consistent manner. If a person does not qualify for NHS continuing healthcare, the NHS may still have a responsibility to contribute to that person's health needs – either by directly providing services or by part-funding the package of support. Where a package of support is provided or funded by both an LA and an NHS body, this is known as a 'joint package' of continuing care (see paragraphs 102–106). A joint package of care could include NHS-funded nursing care and other NHS services that are beyond the powers of a LA to meet. The joint package could also involve both the PCT and the LA contributing to the cost of the care package, or the PCT commissioning and/or providing part of the package. Joint packages of care may be provided in a nursing or residential care home, or in a person's own home.
10. In December 2004, we announced our intention of developing a National Framework, to improve both the consistency of approach towards NHS continuing healthcare and also understanding of it. The White Paper *Our health, our care, our say: a new direction for community services*,¹ published in January 2006, reaffirmed this formal commitment to develop a National Framework and to simplify the interaction between NHS continuing healthcare and NHS-funded nursing care.
11. The major changes set out in the National Framework, published in June 2007, were:
 - a) Instead of each of the 28 SHAs in England having its own rules, tools and processes for determining eligibility for NHS continuing healthcare, there should be one single national approach for the NHS in England, with a common process and national tools to support decision making.

1 www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4127453

- b) Rather than a separate nursing determination to assess an individual's need for NHS-funded nursing care in a nursing home that assigns recipients to one of three bands, there should be a single band for NHS-funded nursing care in a nursing home. The determination of eligibility for NHS-funded nursing care should be integrated into the same framework as the eligibility determination and care planning for NHS continuing healthcare.
- 12.** Within the National Framework, the Department provided a commitment to review the Framework after one year. This revised guidance reflects the issues raised by the review process, together with the wider experience that has been gained through using the Framework in practice. The revised Framework does not change the basis of eligibility decisions for NHS continuing healthcare, nor the overall principles. It does, however, seek to provide greater clarity. It also introduces certain changes to the tools issued alongside the Framework. The changes to the descriptions within the need domains of the Checklist and the Decision Support Tool give greater clarity about the levels and types of need to be considered, and there are changes to the wider information that needs to be recorded. There are also changes to the Fast Track Pathway Tool. The main change, which will be reflected in the revised directions, is that, if an appropriate clinician (see paragraphs 85-86) considers a person to have a primary health need arising from a rapidly deteriorating condition that is entering a terminal phase and completes a Fast Track Pathway Tool, the PCT will be required, on receipt of the completed pathway, to determine that a person is eligible for NHS continuing healthcare, until such time as a full assessment is completed for NHS continuing healthcare, using the Decision Support Tool. The guidance notes for all three tools have also been changed to better clarify the expected approaches to their completion. The amended tools do not reflect any change to the test of eligibility. However, they do seek to improve the ways in which the tools support decision making.
- 13.** This guidance is based on statutory responsibilities, case law, input from the Health Service Ombudsman, and responses received in the course both of the original consultation and the review process. It sets out a process for the NHS, working together with its LA partners wherever practicable, to assess health needs, decide on eligibility for NHS continuing healthcare, and provide that care. It is to be read in conjunction with the national tools to support decision making: the Checklist tool, the Decision Support Tool and the Fast Track Pathway Tool. Separate notes are attached to the tools themselves to explain how they should be applied.
- 14.** This guidance replaces the previous version of the National Framework, published in June 2007.

Legal Framework

Legislation

15. Primary legislation governing the health service does not use the expressions ‘continuing care’, ‘NHS continuing healthcare’ or ‘primary health need’. However, section 1 of the National Health Service Act 2006 requires the Secretary of State to continue the promotion in England of a comprehensive health service, designed to secure improvement in:
- a) the physical and mental health of the people of England; and
 - b) the prevention, diagnosis and treatment of illness.

Furthermore, the Secretary of State is under a duty to provide services for ‘the care of persons suffering from illness and the after-care of persons who have suffered from illness’² throughout England, to whatever extent he or she considers necessary to meet all reasonable requirements. This includes accommodation for the purposes of health services provided under that Act (section 3, particularly section 3(1)(b) and (e) of the National Health Service Act 2006). SHAs and PCTs (among others) carry out this function on behalf of the Secretary of State. What is appropriate to provide as part of the health service therefore has to be considered in the light of the overall purpose of the health service – to improve physical or mental health, and to prevent, diagnose or treat illness.

16. Each LA is under a duty to assess any person who appears to it to be in need of community care services (section 47 of the National Health Service and Community Care Act 1990). Community care services may include residential accommodation for persons who, by reason of age, illness or disability, are in need of care and attention that is not otherwise available to them (section 21 of the National Assistance Act 1948), as well as domiciliary and community-based services to enable people to continue to live in the community. The LA, having regard to the result of that assessment, must then decide whether the person’s needs call for the provision of community care services. The LA must also notify the relevant PCT if, in carrying out the assessment, it becomes apparent to the authority that the person has needs which may fall under the National Health Service Act 2006, and invite the PCT to assist in making the assessment (see section 47(3)(a) of the National Health Service and Community Care Act 1990).

2 ‘Illness’ is defined in the NHS Act 2006 as including any injury or disability requiring medical or dental treatment or nursing.

17. If an NHS body is assessing a person's needs (whether or not potential eligibility for NHS continuing healthcare has been identified) and the assessment indicates a potential need for community care services that may fall within an LA's responsibilities, it should notify the LA of this and consider inviting it to participate in the assessment process.
18. Section 21(8) of the National Assistance Act 1948 states that nothing in section 21 authorises or requires an LA to make any provision that is authorised or required to be provided under the NHS Act 2006 (formerly the NHS Act 1977). This was considered by the Court of Appeal in *Coughlan*, where it was held that an LA is excluded from providing services if the NHS has, in fact, decided to provide those services (see paragraph 22 below for more on the *Coughlan* judgment):

[Section 21] should not be regarded as preventing a local authority from providing any health services. The subsection's prohibitive effect is limited to those health services which, in fact, have been authorised or required to be provided under the 1977 Act. Such health services would not therefore include services which the Secretary of State legitimately decided under section 3(1) of the 1977 Act it was not necessary for the NHS to provide.
19. LAs also have the function of providing welfare services under section 29 of the National Assistance Act 1948 (which includes functions under section 2 of the Chronically Sick and Disabled Persons Act 1970). Section 29(6)(b) of the National Assistance Act 1948 only prohibits LAs from providing such services under section 29 as are 'required' to be provided under the National Health Service Act 2006, and so excludes only those services that must, as a matter of law, be provided under the National Health Service Act 2006.
20. Section 49 of the Health and Social Care Act 2001 prohibits LAs from providing, or arranging for the provision of, nursing care by a registered nurse in connection with the provision by them of community care services. 'Nursing care by a registered nurse' is defined as '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'.
21. Deciding on the balance between LA and PCT responsibilities with respect to continuing care has been the subject of key court judgments.

Case law

- 22.** The decision of the Court of Appeal in *R v North and East Devon Health Authority, ex parte Coughlan* (1999) considered the responsibilities of health authorities and LAs for social service provision, in particular the limits on the provision of nursing care (in a broad sense, i.e. not just registered nursing care) by LAs. This case was decided before the enactment of section 49 of the Health and Social Care Act 2001. The key points from this judgment are set out at Annex B. The court referred to a very general indication of the limit of LA provision in the context of a person living in residential accommodation, saying that if the nursing services are:
- a) merely incidental or ancillary to the provision of the accommodation that an LA is under a duty to provide, pursuant to section 21 of the National Assistance Act 1948; and
 - b) of a nature that an authority whose primary responsibility is to provide social services can be expected to provide
- then such nursing services can be provided under section 21 of the National Assistance Act 1948.
- 23.** Since the enactment of the Health and Social Care Act 2001, care from a registered nurse cannot be provided by the LA as part of community care services. Nevertheless, the extent of care supported by the NHS-funded nursing care contribution is still to be considered as ‘incidental and ancillary’ in the sense described in *Coughlan*.
- 24.** Eligibility for NHS continuing healthcare must always be considered prior to any consideration of eligibility for NHS-funded nursing care. The interaction between NHS continuing healthcare and NHS-funded nursing care was further considered by the High Court in *R v Bexley NHS Trust, ex parte Grogan* (2006). The key points from this judgment are set out at Annex C.

Primary Health Need

25. To assist in deciding which treatment and other health services it is appropriate for the NHS to provide under the National Health Service Act 2006, and to distinguish between those and the services that LAs may provide under section 21 of the National Assistance Act 1948, the Secretary of State has developed the concept of a 'primary health need'. Where a person's primary need is a health need, they are eligible for NHS continuing healthcare. Deciding whether this is the case involves looking at the totality of the relevant needs. Where an individual has a primary health need and is therefore eligible for NHS continuing healthcare, the NHS is responsible for providing all of that individual's assessed needs – including accommodation, if that is part of the overall need.
26. There should be no gap in the provision of care. People should not find themselves in a situation where neither the NHS nor the relevant LA (subject to the person meeting the relevant means test and having needs that fall within the appropriate local Fair Access to Care bandings) will fund care, either separately or together. Therefore, the 'primary health need' test should be applied, so that a decision of ineligibility for NHS continuing healthcare is only possible where, taken as a whole, the nursing or other health services required by the individual:
 - a) are no more than incidental or ancillary to the provision of accommodation which LA social services are, or would be but for a person's means, under a duty to provide; and
 - b) are not of a nature beyond which an LA whose primary responsibility it is to provide social services could be expected to provide
27. There are certain limitations to this test, which was originally indicated in *Coughlan*: neither the PCT nor the LA can dictate what the other agency should provide, and the *Coughlan* judgment itself focused only on general and registered nursing needs.
28. Instead, a practical approach to eligibility is required – one that will apply to a range of different circumstances, including situations in which the 'incidental or ancillary' test is not applicable because, for example, the person is to be cared for in their own home. Certain characteristics of need – and their impact on the care required to manage them – may help determine whether the 'quality' or 'quantity' of care required is more than the limits of an LA's responsibilities, as outlined in *Coughlan*:

- **Nature:** This describes the particular characteristics of an individual's needs (which can include physical, mental health or psychological needs) and the type of those needs. This also describes the overall effect of those needs on the individual, including the type ('quality') of interventions required to manage them.
- **Intensity:** This relates both to the extent ('quantity') and severity ('degree') of the needs and to the support required to meet them, including the need for sustained/ongoing care ('continuity').
- **Complexity:** This is concerned with how the needs present and interact to increase the skill required to monitor the symptoms, treat the condition(s) and/or manage the care. This may arise with a single condition, or it could include the presence of multiple conditions or the interaction between two or more conditions. It may also include situations where an individual's response to their own condition has an impact on their overall needs, such as where a physical health need results in the individual developing a mental health need.
- **Unpredictability:** This describes the degree to which needs fluctuate and thereby create challenges in managing them. It also relates to the level of risk to the person's health if adequate and timely care is not provided. Someone with an unpredictable healthcare need is likely to have either a fluctuating, unstable or rapidly deteriorating condition.

Each of these characteristics may, alone or in combination, demonstrate a primary health need, because of the quality and/or quantity of care that is required to meet the individual's needs. The totality of the overall needs and the effects of the interaction of needs should be carefully considered.

There will be some circumstances where the quantity or the quality of the individual's overall general nursing care needs will indicate a primary health need, and thus eligibility for NHS continuing healthcare. PCTs and LAs should be mindful of the extent and nature of NHS-funded nursing care, as set out in the *NHS-Funded Nursing Care Practice Guide 2007*.³

29. It is also important that deterioration is taken into account when considering eligibility, including circumstances where deterioration might reasonably be regarded as likely in the near future. This can be reflected in several ways:
- Where it is considered that deterioration can reasonably be anticipated to occur before the next planned review, this should be documented and taken into account. This could result in immediate eligibility for NHS continuing healthcare

3 www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_078827

(i.e. before the deterioration has actually occurred). The anticipated deterioration could be indicative of complex or unpredictable needs.

- Where eligibility is not established at the present time, the likely deterioration could be reflected in a recommendation for an early review, in order to establish whether the individual then satisfies the eligibility criteria.
 - If an individual has a rapidly deteriorating condition that may be entering a terminal phase, they may need NHS continuing healthcare funding to enable their needs to be met urgently (e.g. to allow them to go home to die or appropriate end of life support to be put in place). This would be a primary health need because of the rate of deterioration. In all cases where an individual has such needs, consideration should be given to use of the Fast Track Pathway Tool, as set out in paragraphs 85–94.
 - Even when an individual does not satisfy the criteria for use of the Fast Track Pathway Tool, one or more of the characteristics listed in paragraph 28 may well apply to those people approaching the end of their lives, and eligibility should always be considered.
- 30.** Good practice in end of life care is currently supported through the End of Life Care Programme. The principles of the national End of Life Care Strategy⁴ should be reflected in all NHS continuing healthcare cases that involve individuals with an end of life condition.
- 31.** To minimise variation in interpretation of these principles, and to inform consistent decision making, we have, in conjunction with stakeholders, developed the national Decision Support Tool. The Decision Support Tool supports practitioners in identifying these needs, by indicating a level of need that could constitute a primary health need. The Decision Support Tool, combined with practitioners' own experience and professional judgement, should enable them to apply the primary health need test in practice, in a way that is consistent with the limits on what can lawfully be provided by an LA, in accordance with the *Coughlan* and the *Grogan* judgments.
- 32.** Further details about the Decision Support Tool and its application are set out below (paragraphs 67–78) and in the notes accompanying the tool. Before using the Decision Support Tool, practitioners should ensure that they have obtained evidence from all the necessary assessments (comprehensive and specialist), in line with the core values and principles outlined below.

⁴ www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277

Core Values and Principles

33. The process of assessment and decision making should be person centred. This means placing the individual, their perception of their support needs, and their preferred models of support at the heart of the assessment and care-planning process. When deciding on how their needs are met, the individual's wishes and expectations of how and where the care is delivered should be documented and taken into account, along with the risks of different types of provision and fairness of access to resources.
34. Access to assessment, decision making and provision should be fair and consistent. There should be no discrimination on the grounds of race, disability, gender, age, sexual orientation, religion or belief, or type of health need (for example, whether the need is physical, mental or psychological). PCTs are responsible for ensuring that discrimination does not occur and should use effective auditing to monitor this matter (see the section on 'Governance' below).
35. Assessments of eligibility for NHS continuing healthcare and NHS-funded nursing care should be organised so that the individual being assessed and their representative understand the process, and receive advice and information that will maximise their ability to participate in informed decision making about their future care. Decisions and rationales that relate to eligibility should be transparent from the outset: for individuals, carers, family and staff alike.

Consent

36. As with any examination or treatment, the individual's informed consent should be obtained before the start of the process to determine eligibility for NHS continuing healthcare.⁵
37. It should be made explicit to the individual whether their consent is being sought for a specific aspect of the eligibility consideration process (e.g. completion of the Checklist) or for the full process. It should also be noted that individuals may withdraw their consent at any time in the process.
38. If an individual does not consent to assessment of eligibility for NHS continuing healthcare, the potential effect this will have on the ability of the NHS and the LA to provide appropriate services should be carefully explained to them. The fact that

5 www.dh.gov.uk/en/Publichealth/Scientificdevelopmentgeneticsandbioethics/Consent/index.htm

an individual declines to be considered for NHS continuing healthcare does not, in itself, mean that an LA has an additional responsibility to meet their needs, over and above the responsibility it would have had if consent had been given. Where there are concerns that an individual may have significant ongoing needs, and that the level of appropriate support could be affected by their decision not to give consent, the appropriate way forward should be considered jointly by the PCT and the LA, taking account of each organisation's legal powers and duties. It may be appropriate for the organisations involved to seek legal advice.

Capacity

39. If there is a concern that the individual may not have capacity to give consent, this should be determined in accordance with the Mental Capacity Act 2005 and the associated code of practice.⁶ PCTs should be particularly aware of the five principles of the Act:
- **A presumption of capacity:** Every adult has the right to make his or her own decisions and must be presumed to have capacity to do so, unless it is proved otherwise.
 - **Individuals being supported to make their own decisions:** A person must be given all practicable help before anyone treats them as not being able to make their own decisions.
 - **Unwise decisions:** Just because an individual makes what might be seen as an unwise decision, they should not be treated as lacking capacity to make that decision.
 - **Best interests:** An act done or decision made under the Act for or on behalf of a person who lacks capacity must be in their best interests.
 - **Least restrictive option:** Anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms.
40. It is important to be aware that just because an individual may have significant difficulty in expressing their views this does not in itself mean that they lack capacity. Appropriate support and adjustments should be made available, in compliance with the Mental Capacity Act 2005 and with disability discrimination legislation.
41. If the person lacks the mental capacity either to refuse or to consent, a 'best interests' decision should be taken (and recorded) as to whether or not to proceed with assessment of eligibility for NHS continuing healthcare. Those making this decision

⁶ www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/MentalCapacity/MentalCapacityAct2005/DH_073511

should bear in mind the expectation that everyone who is potentially eligible for NHS continuing healthcare should have the opportunity to be considered for eligibility. A third party cannot give or refuse consent for an assessment of eligibility for NHS continuing healthcare on behalf of a person who lacks capacity, unless they have a valid and applicable Lasting Power of Attorney (Welfare) or they have been appointed a Welfare Deputy by the Court of Protection.

42. Where a ‘best interests’ decision needs to be made, the PCT must consult with any relevant third party who has a genuine interest in the person’s welfare. This will normally include family and friends.

Advocacy

43. The Mental Capacity Act 2005 created a new statutory service: the Independent Mental Capacity Advocate (IMCA) service. Its purpose is to help vulnerable people who lack capacity and who are facing important decisions made by the NHS and LAs about serious medical treatment or change of residence – for example, moving to a hospital or care home. NHS bodies and LAs have a duty under the Act to instruct and consult the IMCA if those concerned are people who lack capacity in relation to the relevant decision and who have no family or friends that are available (or appropriate) for consultation on their behalf.
44. Even if an individual does not meet the criteria for use of the IMCA service, and regardless of whether or not they lack capacity, they may wish to be supported by an advocate. PCTs should ensure that individuals are made aware of local advocacy and other services that may be able to offer advice and support, and should also consider whether any strategic action is needed to ensure that adequate advocacy services are available to support those who are eligible and potentially eligible for NHS continuing healthcare. In addition, any person may choose to have a family member or other person (who should operate independently of LAs and NHS bodies) to act as an advocate on their behalf.

Carers

45. PCTs and LAs should bear in mind that a carer who provides (or intends to provide) substantial care on a regular basis has a right to have their needs as a carer assessed (Carers and Disabled Children Act 2000, as amended by the Carers (Equal Opportunities) Act 2004). Should a PCT identify a carer in the course of its assessment process, it should inform them of their right to a carer’s assessment and advise them to contact their LA – or, with their permission, refer them for this purpose. PCTs and LAs should be mindful of the approaches set out in the national

strategy for carers – *Carers at the heart of 21st century families and communities*.⁷

It should also be noted that the NHS Operating Framework 2009/10 states:⁸

The Carers' Strategy sets out how we can ensure that we support carers. One key requirement is that PCTs should work with their local authority partners and publish joint plans on how their combined funding will support breaks for carers, including short breaks, in a personalised way.

Other eligibility issues

46. Eligibility for NHS continuing healthcare is based on an individual's assessed health needs. The diagnosis of a particular disease or condition is not in itself a determinant of eligibility for NHS continuing healthcare.
47. NHS continuing healthcare may be provided by PCTs in any setting (including, but not limited to, a care home, hospice or the person's own home). Eligibility for NHS continuing healthcare is, therefore, not determined or influenced either by the setting where the care is provided or by the characteristics of the person who delivers the care. The decision-making rationale should not marginalise a need just because it is successfully managed: well-managed needs are still needs. Only where the successful management of a healthcare need has permanently reduced or removed an ongoing need will this have a bearing on NHS continuing healthcare eligibility.
48. Financial issues should not be considered as part of the decision on an individual's eligibility for NHS continuing healthcare, and it is important that the process of considering and deciding eligibility does not result in any delay to treatment or to appropriate care being put in place.
49. The reasons given for a decision on eligibility should not be based on:
 - the person's diagnosis;
 - the setting of care;
 - the ability of the care provider to manage care;
 - the use (or not) of NHS-employed staff to provide care;
 - the need for/presence of 'specialist staff' in care delivery;
 - the fact that a need is well managed;

⁷ www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085345

⁸ www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_091445

- the existence of other NHS-funded care; or
 - any other input-related (rather than needs-related) rationale.
- 50.** The NHS's responsibility to commission, procure or provide care, including NHS continuing healthcare, is not indefinite, as needs could change. This should be made clear to the individual and their family. Regular reviews are built into the process to ensure that the care package continues to meet the person's needs.

Assessments

- 51.** Establishing that an individual's primary need is a health need requires a clear, reasoned decision, based on evidence of needs from a comprehensive assessment. A good-quality assessment that looks at all of the individual's needs 'in the round' – including the ways in which they interact with one another – is crucial both to addressing these needs and to determining eligibility for NHS continuing healthcare. The individual and (where appropriate) their representative should be enabled to play a central role in the assessment process.
- 52.** The assessment of an individual's needs informs the assessment of whether or not they are entitled to NHS continuing healthcare. However, regardless of whether the individual is determined to be eligible for NHS continuing healthcare, PCTs and LAs should always consider whether the assessment of needs has identified issues that require action to be taken. For example, if an assessment of needs indicates that the individual has significant communication difficulties, referral to a speech and language service should be considered.
- 53.** Local assessment arrangements and processes differ around the country, though a number of models have formed the basis for assessment and care and support planning processes. The Single Assessment Process for older people⁹ has been extended in many areas to cover all adults, and the Care Programme Approach¹⁰ is more widely used in mental health. The principles on which these are founded, together with more recent progress around personalisation and self-directed support, have provided the basis for development of a Common Assessment Framework for adults.¹¹ The proposals, which focused on improved sharing of assessment and care and support planning information, were subject to a wide consultation from January to April 2009, and the practical aspects of development and implementation are being evaluated through a number of local LA-led demonstrator sites.

⁹ www.dh.gov.uk/en/SocialCare/Chargingandassessment/SingleAssessmentProcess/index.htm

¹⁰ www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083647

¹¹ www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/CommonAssessmentFrameworkforAdults/index.htm

Person-centred plans¹² (which were originally developed for use by people with learning disabilities, but which can be used by anyone – and are increasingly being used more widely) are not assessments. Rather they represent the individual's own view of their desired outcomes and support needs. As such, they can offer key evidence to be considered when completing both the assessment and the Decision Support Tool. Health action plans and health checks¹³ can also provide useful evidence.

12 Further details may be found in *Valuing People: A New Strategy for Learning Disability for the 21st Century*, at www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009153

13 Further details may be found in *Health Action Planning and Health Facilitation for people with learning disabilities: good practice guidance*, at www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_096505

Eligibility Consideration

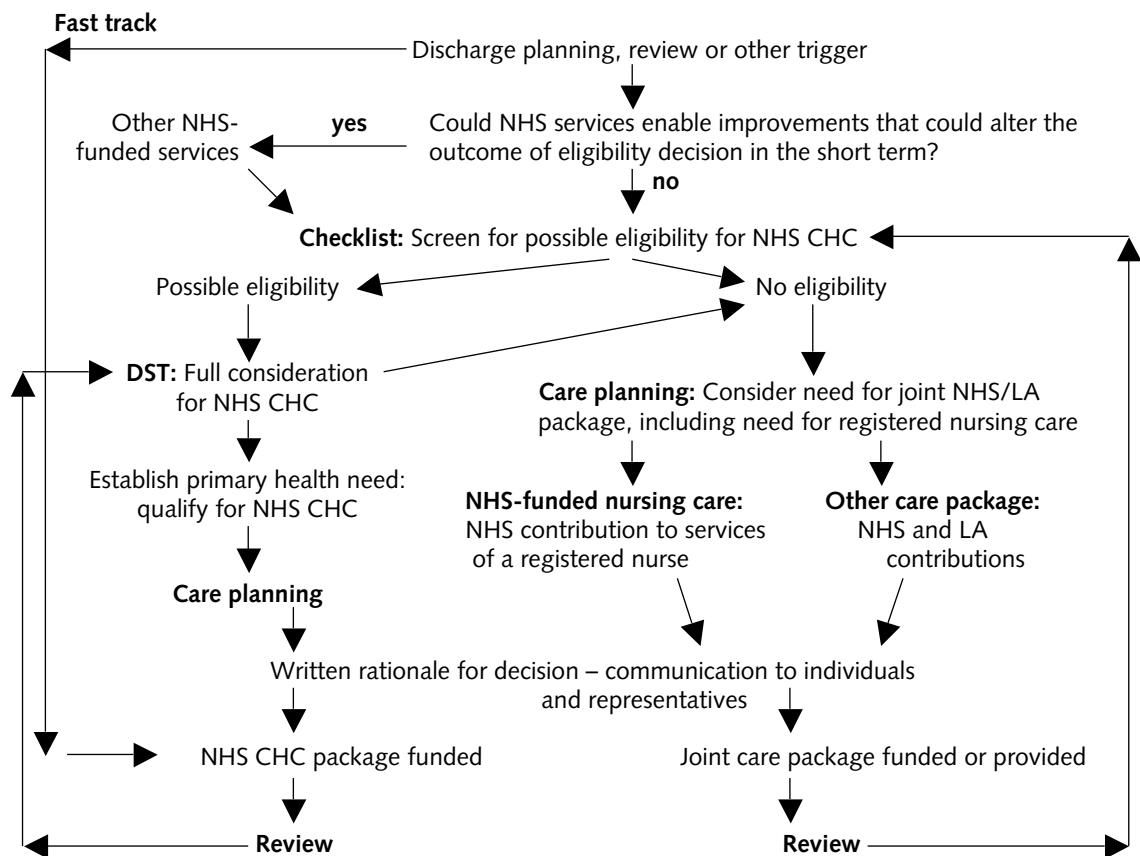


Figure 1: Overall process for determining eligibility for NHS continuing healthcare (NHS CHC) and the NHS elements of joint packages of care (including NHS-funded nursing care). Please see main text for explanation.

54. In a hospital setting, before an NHS body gives notice of an individual's case to an LA, in compliance with section 2(2) of the Community Care (Delayed Discharges etc.) Act 2003, it 'must take reasonable steps to ensure that an assessment for NHS continuing healthcare is carried out in all cases where it appears to the body that the patient may have a need for such care'. This should be in consultation, as appropriate, with the relevant LA.
55. NHS bodies should have clear arrangements about how their responsibilities are exercised in relation to delayed discharge and NHS continuing healthcare. PCTs should ensure that local protocols are developed between themselves, other NHS bodies, LAs and other relevant partners. These should set out each organisation's

role and how its responsibilities are to be exercised in relation to delayed discharge and NHS continuing healthcare, including its responsibilities with regard to the decision making on eligibility. There should be processes in place to identify those individuals for whom it is appropriate to use the Checklist. and, where the Checklist indicates that they may have needs that would make them eligible for continuing healthcare, for full assessment of eligibility to then take place.

- 56.** Assessment of eligibility for NHS continuing healthcare can take place in either hospital or non-hospital settings. It should always be borne in mind that assessment of eligibility that takes place in an acute hospital may not always reflect an individual's capacity to maximise their potential. This could be because, with appropriate support, that individual has the potential to recover further in the near future. It could also be because it is difficult to make an accurate assessment of an individual's needs while they are in an acute services environment. Anyone who carries out an assessment of eligibility for NHS continuing healthcare should always consider whether there is further potential for rehabilitation and for independence to be regained, and how the outcome of any treatment or medication may affect ongoing needs.
- 57.** In order to address this issue and ensure that unnecessary stays on acute wards are avoided, there should be consideration of whether the provision of further NHS-funded services is appropriate. This might include therapy and/or rehabilitation, if that could make a difference to the potential of the individual in the following few months. It might also include intermediate care or an interim package of support in an individual's own home or in a care home. In such situations, assessment of eligibility for NHS continuing healthcare should usually be deferred until an accurate assessment of future needs can be made. The interim services (or appropriate alternative interim services if needs change) should continue in place until the determination of eligibility for NHS continuing healthcare has taken place. There must be no gap in the provision of appropriate support to meet the individual's needs.
- 58.** Where NHS-funded care, other than on an acute ward, is the next appropriate step after hospital treatment, this does not trigger the responsibilities under the Community Care (Delayed Discharges etc.) Act 2003.
- 59.** Whenever an individual outside a hospital setting is having their health or social needs assessed or reviewed by an NHS body or an LA, consideration should always be given to whether their needs suggest that it might be appropriate to use the Checklist (see below) to identify whether or not there is potential eligibility for NHS continuing healthcare.

Checklist

60. The first step in the process for most people will be a screening process, using the NHS continuing healthcare Checklist – unless it is deemed appropriate for the Fast Track Pathway Tool to be used at this stage (see paragraphs 85–94) or for other NHS-funded services to be provided (see paragraph 57). In an acute hospital setting, the Checklist should not be completed until the individual’s needs on discharge are clear. The purpose of the Checklist is to encourage proportionate assessments, so that resources are directed towards those people who are most likely to be eligible for NHS continuing healthcare, and to ensure that a rationale is provided for all decisions regarding eligibility.
61. Before the Checklist is applied, it is necessary to ensure that the individual and (where appropriate) their representative understand that the Checklist does not indicate a likelihood that the individual will be eligible for NHS continuing healthcare – only that they are entitled to **consideration** for eligibility.
62. The threshold at this stage of the process has intentionally been set low, in order to ensure that all those who require a full consideration of their needs have this opportunity.
63. A nurse, doctor, other qualified healthcare professional or social worker could apply the Checklist to refer individuals for a full assessment of eligibility for NHS continuing healthcare from either a community or a hospital setting. Whoever applies the checklist should be familiar with, and have regard to, the content and principles of this guidance and the Decision Support Tool (see paragraphs 67–78).
64. Where the Checklist has been used as part of the process of discharge from an acute hospital, and has indicated a need for full assessment of eligibility (or where a Checklist is not used, a full assessment of eligibility would otherwise take place), a decision may be made at this stage first to provide other services (such as those set out in paragraph 57 above) and then to carry out a full assessment of eligibility at a later stage. This should be recorded. The relevant PCT should ensure that full assessment of eligibility is carried out once it is possible to make a reasonable judgement about the individual’s ongoing needs. This full consideration should be completed in the most appropriate setting – whether another NHS institution, the individual’s home or some other care setting. In the interim, the PCT retains responsibility for funding appropriate care.
65. No individual should be left without appropriate support while they await the outcome of the decision-making process. Further guidance on responsibilities whilst awaiting the outcome of the decision-making process will be issued later in 2009.

- 66.** Whatever the outcome of the Checklist – whether or not a referral for a full assessment for NHS continuing healthcare eligibility is considered necessary – the decision (including the reasons why the decision was reached) should be communicated clearly and in writing to the individual and (where appropriate) their representative, as soon as is reasonably practicable. Where the outcome is not to proceed to full assessment of eligibility, the written decision should also contain details of the individual’s right to ask the PCT to reconsider the decision. The PCT should give such requests due consideration, taking account of all the information available, including additional information from the individual or carer. A clear and written response should be given to the individual and (where appropriate) their representative, as soon as is reasonably practicable. The response should also give details of the individual’s rights under the NHS complaints procedure.¹⁴

Decision Support Tool

- 67.** Once an individual has been referred for a full assessment for NHS continuing healthcare (following use of the Checklist or, if a Checklist is not used in an individual case, following direct referral for full consideration), then, irrespective of the individual’s setting, the PCT has responsibility for coordinating the whole process until the decision on funding has been made and a care plan agreed. The PCT should identify an individual (or individuals) to carry out this coordination role. By mutual agreement, the coordinator may either be a PCT member of staff or be from an external organisation.
- 68.** Even when there is no eligibility for NHS continuing healthcare, care planning for those individuals with ongoing needs, including the consideration of need for NHS-funded nursing care, will still be necessary (see the section on ‘Commissioning, Care Planning and Provision’ below).
- 69.** The Decision Support Tool should be used following a comprehensive multidisciplinary assessment of an individual’s health and social care needs and their desired outcomes. If a multidisciplinary assessment has recently already been completed, this may be used; but care should be taken to ensure that it provides an accurate reflection of current need.
- 70.** The multidisciplinary assessment that informs completion of the Decision Support Tool should be carried out with the knowledge and consent of the individual, and they should be given every opportunity to participate in the assessment. The individual should be given the option of being supported or represented by a carer or advocate, if they so wish. The assessment process should draw on those who have direct knowledge of the individual and their needs. It should also make use of existing

¹⁴ <http://www.nhs.uk/aboutNHSChoices/pages/Howtocomplaincompliment.aspx>

specialist assessments, and should make referrals for other specialist assessments whenever that is appropriate in light of the individual's care needs.

71. The Decision Support Tool is not an assessment in itself. Rather, it is a way of bringing together and applying evidence in a single practical format, to facilitate consistent, evidence-based decision making regarding NHS continuing healthcare eligibility. The evidence and the decision-making process should be accurately and fully recorded.
72. The multidisciplinary assessment should be in such a format that it can also be used to assist PCTs and LAs to meet care needs regardless of eligibility for NHS continuing healthcare.
73. The involvement of LA colleagues as well as health professionals in the assessment process will streamline the process of care planning and will make decision making more effective and consistent. Directions require that, as far as is reasonably practicable, PCTs should consult with the relevant LA before making any decision about an individual's eligibility for NHS continuing healthcare. If an LA is consulted, there is a requirement for it to provide advice and assistance to the PCT, as far as is reasonably practicable. If an LA has carried out a community care assessment, it should, as far as is reasonably practicable, use the information obtained from it when providing advice and assistance to the PCT. LAs should also advise PCTs of any information they have on changed needs since the community care assessment was completed. As with any assessments that they carry out, LAs should not allow an individual's financial circumstances to affect its decision to participate in a joint assessment.
74. The Decision Support Tool is designed to ensure that the full range of factors that have a bearing on an individual's eligibility are taken into account in reaching the decision. The tool provides practitioners with a framework to bring together and record the various needs in 12 'care domains', or generic areas of need. The domains are sub-divided into statements of need, representing low, moderate, high, severe or priority levels of need, depending on the domain. The care domains are:
 1. Behaviour
 2. Cognition
 3. Psychological and emotional needs
 4. Communication
 5. Mobility
 6. Nutrition – food and drink
 7. Continence
 8. Skin (including tissue viability)
 9. Breathing

- 10. Drug therapies and medication: symptom control
- 11. Altered states of consciousness
- 12. Other significant care needs.

75. Completion of the tool should result in an overall picture of the individual’s needs that captures their nature, and their complexity, intensity and/or unpredictability – and thus the quality and/or quantity (including continuity) of care required to meet the individual’s needs. Figure 2 indicates how the domains in the Decision Support Tool can illustrate the complexity, intensity and unpredictability of needs. The overall picture, and the descriptors within the domains themselves, also relate to the nature of needs.

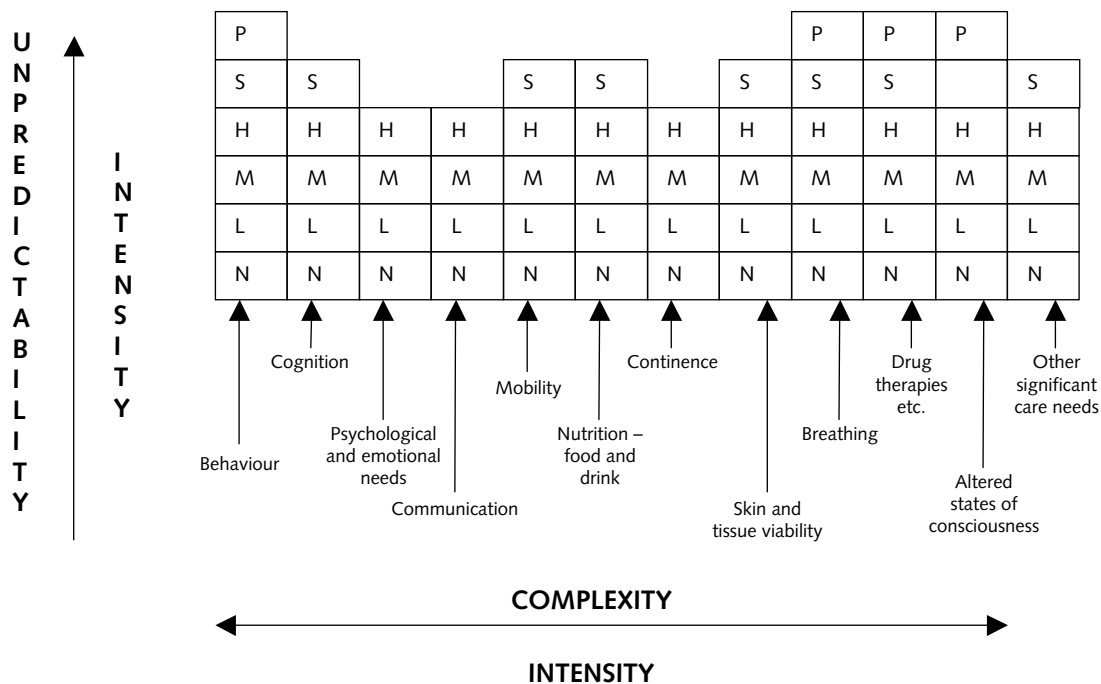


Figure 2: How the domains help build up a picture of complexity, intensity and unpredictability. Within the 12 care domains, N = No, L = Low, M = Moderate, H = High, S = Severe and P = Priority.

- 76. In certain cases, an individual may have particular needs that are not easily categorised by the care domains described here. In such circumstances, it is the responsibility of the assessors to determine the extent and type of the need and to take that need into account (and record it in the 12th care domain) when deciding whether a person has a primary health need.
- 77. As is described in the Decision Support Tool, the multidisciplinary team should use it to set out the evidence and enable them to consider not just the overall needs, but also the interaction between the needs, and evidence from relevant risk assessments.

Although the tool supports the process of determining eligibility, and ensures consistent and comprehensive consideration of an individual's needs, it cannot directly determine eligibility. Indicative guidelines as to threshold are set out in the tool (for example, if one area of need is at Priority level, then this demonstrates a primary health need), but these are not to be viewed prescriptively. Professional judgement should be exercised in all cases to ensure that the individual's overall level of need is correctly determined. The tool is to aid decision making in terms of whether the nature, complexity, intensity or unpredictability of a person's needs are such that the individual has a primary health need.

78. Once the multidisciplinary team has reached agreement, it should make a recommendation to the PCT on eligibility.

Decision making

79. PCTs should be aware of cases that have indicated circumstances in which eligibility for NHS continuing healthcare should have been determined, and where such an outcome would be expected if the same facts were considered in an assessment for NHS continuing healthcare under the National Framework (e.g. *Coughlan* or those cases in the Health Service Ombudsman's report on NHS funding for the long-term care of older and disabled people). However, they should be wary of trying to draw generalisations about eligibility for NHS continuing healthcare from the limited information they may have about those cases. There is no substitute for a careful and detailed assessment of the needs of the individual whose eligibility is in question.
80. Many PCTs use a panel to ensure consistency and quality of decision making. However, a panel should not fulfil a gate-keeping function, and nor should it be used as a financial monitor. Only in exceptional circumstances, and for clearly articulated reasons, should the multidisciplinary team's recommendation not be followed. A decision not to accept the recommendation should never be made by one person acting unilaterally.
81. PCTs may ask a multidisciplinary team to carry out further work on a Decision Support Tool if it is not completed fully or if there is a significant lack of consistency between the evidence recorded in the Decision Support Tool and the recommendation made. However, PCTs should not refer a case back, or decide not to accept a recommendation, simply because the multidisciplinary team has made a recommendation that differs from the one that those who are involved in making the final decision would have made, based on the same evidence.
82. PCTs should not make decisions in the absence of recommendations on eligibility from the multidisciplinary team, except where exceptional circumstances require

an urgent decision to be made. Because the final eligibility decision should be independent of budgetary constraints, finance officers should not be part of a decision-making panel.

- 83.** As part of their responsibility to ensure consistent application of the National Framework, PCTs may review the pattern of recommendations made by multidisciplinary teams, in order to improve practice. However, this should be carried out separately from the approval of recommendations in individual cases.
- 84.** The time that elapses between the Checklist (or, where no Checklist is used, other notification of potential eligibility) being received by the PCT and the funding decision being made should, in most cases, not exceed 28 days. In acute services, it may be appropriate for the process to take significantly less than 28 days if an individual is otherwise ready for discharge. PCTs can help manage this process by ensuring that potential NHS continuing healthcare eligibility is actively considered as a central part of the discharge planning process, and also by considering whether it would be appropriate to provide interim or other NHS-funded services, as set out in paragraph 57 above.

When there are valid and unavoidable reasons for the process taking longer, timescales should be clearly communicated to the person and (where appropriate) their carers and/or representatives.

Fast Track Pathway Tool

- 85.** Occasionally, individuals with a rapidly deteriorating condition that may be entering a terminal phase, and with an increasing level of dependency, will require 'fast-tracking' for immediate provision of NHS continuing healthcare because they need an urgent package of care. The Fast Track Pathway Tool should be completed by an appropriate clinician, who should give the reasons why the person meets the conditions required for the fast-tracking decision. 'Appropriate clinicians' are those persons who are, pursuant to the NHS Act 2006, responsible for an individual's diagnosis, treatment or care and who are medical practitioners (such as consultants, registrars or GPs) or registered nurses. The clinician should have an appropriate level of knowledge or experience of the type of health needs, so that they are able to comment reasonably on whether the individual has a rapidly deteriorating condition that may be entering a terminal phase, and an increasing level of dependency.
- 86.** Appropriate clinicians can include clinicians employed in voluntary and independent sector organisations that have a specialist role in end of life needs (for example, hospices), provided they are offering services pursuant to the NHS Act 2006. Others involved in supporting those with end of life needs, including those in

wider voluntary and independent sector organisations, may identify the fact that the individual has needs for which use of the Fast Track Pathway Tool would be appropriate. They should contact the appropriate clinician who is responsible for the diagnosis, care or treatment of the individual and ask for consideration to be given to completion of the Fast Track Pathway Tool.

- 87.** The completed Fast Track Pathway Tool should be supported by a prognosis, if available. However, strict time limits that base eligibility on some specified expected length of life remaining should not be imposed: it is the responsibility of the assessor to make a decision based on the relevant facts of the case.
- 88.** Where a recommendation is made for an urgent package of care via the fast-track process, this should be accepted and actioned immediately by PCTs. It is not appropriate for individuals to experience delay in the delivery of their care package while disputes over the use of the Fast Track Pathway Tool are resolved. PCTs should carefully monitor use of the tool and raise any specific concerns with clinicians, teams and organisations. However, this should be treated as a separate matter from the task of arranging for service provision in the individual case. No one who has been identified through the fast-track process as eligible for NHS continuing healthcare should have this funding removed without the eligibility being reviewed in accordance with the review processes set out in paragraphs 138–145. The review should include completion of a Decision Support Tool by a multidisciplinary team, including them making a recommendation on future eligibility.
- 89.** The purpose of the Fast Track Pathway Tool is to ensure that individuals with a rapidly deteriorating condition that may be entering a terminal phase, and with an increasing level of dependency, are supported to be in their preferred place of care as quickly as possible, without encountering delay as they wait for the full NHS continuing healthcare eligibility process to be completed. This overall process should be carefully and sensitively explained to the individual and (where appropriate) their representative. Careful and sensitive decision making is essential in order to avoid the undue distress that might result from a person moving in and out of NHS continuing healthcare eligibility within a very short period of time.
- 90.** Where an individual who is receiving services from use of the Fast Track Pathway Tool is expected to die in the very near future, PCTs should pay particular attention to consideration of whether it is appropriate for the PCT to continue to take responsibility for the care package until the end of life.
- 91.** It is important to bear in mind that this is not the only way that someone can qualify for NHS continuing healthcare towards the end of their life. The Decision Support Tool asks practitioners to document deterioration (including observed and

likely deterioration) in a person's condition, so that they can take this into account in determining eligibility using the Decision Support Tool. However, this should not be used as a means of circumventing use of the Fast Track Pathway Tool when individuals satisfy the criteria for its use.

92. Where deterioration can be reasonably anticipated to take place in the near future, this should also be taken into account, in order to avoid the need for unnecessary or repeat assessments.
93. In end of life cases, PCTs and LAs should take particular account of paragraphs 135–137 regarding person-centred commissioning and procurement arrangements.
94. NHS continuing healthcare assessments, care planning and commissioning for those with end of life needs should be carried out in an integrated manner, as part of the individual's overall end of life care pathway, and should reflect the approaches set out in the national End of Life Care Strategy, with full account being taken of patient preferences, including those set out in advance care plans.

Commissioning, Care Planning and Provision

Commissioning and care planning

95. It is the responsibility of the PCT to plan strategically, specify outcomes and procure services, and manage demand and provider performance for all services that are required to meet the needs of all individuals who qualify for NHS continuing healthcare, and for the healthcare part of a joint care package (see the subsection on joint packages of health and social care services in 'Access to Other NHS-funded Services' below). The services commissioned should include an ongoing case-management role for all those entitled to NHS continuing healthcare, as well as for the NHS elements of joint packages, including an assessment and review of individual patient needs.
96. As with all service contracts, commissioners are responsible for monitoring quality, access and patient experience within the context of provider performance. This is particularly important in this instance, as ultimate responsibility for arranging and monitoring the services required to meet the needs of those who qualify for NHS continuing healthcare rests with PCT commissioners. PCTs should ensure that there is clarity on the respective responsibilities of commissioners and providers with regard to NHS continuing healthcare.
97. PCTs should take a strategic as well as an individual approach to fulfilling their NHS continuing healthcare commissioning responsibilities, and should carry them out within the overall context of world class commissioning. PCTs may wish to commission NHS-funded care from a wide range of providers, in order to secure high-quality services that offer value for money. As part of their joint commissioning responsibility, we would expect PCTs and LAs to work in partnership, and to share information (where reasonable) to enable them to commission the most appropriate packages of care for their populations.
98. Many individuals in receipt of NHS continuing healthcare and joint care packages will have long-term conditions. PCTs and LAs should take into account the policy set out in *Supporting People with Long Term Conditions: Commissioning Personalised Care Planning*.¹⁵ The approaches set out may also be helpful in care planning for those in receipt of NHS continuing healthcare who do not have a long-term condition.

¹⁵ www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093354

The individual and personalised approaches described in *Valuing People Now*¹⁶ for people with learning disabilities are similarly relevant. Care planning for needs to be met under NHS continuing healthcare should not be carried out in isolation from care planning to meet other needs, and, wherever possible, a single, integrated and personalised care plan should be developed.

Provision

- 99.** Whether or not a person is eligible for NHS continuing healthcare, if they have ongoing care needs, the care planning process helps in the decision on how best to meet those needs.
- 100.** Where a person qualifies for NHS continuing healthcare, the package to be provided is that which the PCT assesses is appropriate for the individual's needs. Although the PCT is not bound by the views of the LA on what services the individual requires, the LA's assessment under section 47 of the National Health Service and Community Care Act 1990, or its contribution to a joint assessment, will be important in identifying the individual's needs and, in some cases, the options available for meeting them.
- 101.** The LA is, however, not prevented from providing services, subject to the limits outlined in paragraphs 16–21. Indeed, in some cases, individual arrangements may have to be reached between LAs and PCTs with respect to the provision of services. This may be particularly relevant if the person is to be cared for in a community setting.

¹⁶ www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093377

Access to Other NHS-funded Services

Joint packages of health and social care services

- 102.** If a person is not eligible for NHS continuing healthcare, they may receive a package of health and social care (rather than be fully funded by the NHS).
- 103.** There will be some individuals who, although they are not entitled to NHS continuing healthcare, have needs identified through the Decision Support Tool that are not of a nature that an LA can solely meet or are beyond the powers of an LA to solely meet. PCTs should work in partnership with their LA colleagues to agree their respective responsibilities in a joint package of care.
- 104.** Apart from NHS-funded nursing care, additional health services may also be funded by the NHS, if these are identified and agreed as part of an assessment and care plan. The range of services that the NHS is expected to arrange and fund includes, but is not limited to:
- primary healthcare;
 - assessment involving doctors and registered nurses;
 - rehabilitation and recovery (where this forms part of an overall package of NHS care, as distinct from intermediate care);
 - respite healthcare;
 - community health services;
 - specialist support for healthcare needs; and
 - palliative care and end of life healthcare.
- 105.** According to each LA's Fair Access to Care¹⁷ criteria, it will be responsible for providing such social care, including personal care, as can lawfully be provided following the *Coughlan* limits set out in paragraph 22 (see also Annex B).
- 106.** With respect to other types of joint package, the extent to which each service should provide care is for NHS and LA partners to agree, bearing in mind the fact that LAs

¹⁷ www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009653

can provide some health services, subject to the legal limitations set out in paragraphs 16–21 above.

Entitlement to other NHS-funded care

- 107. Those in receipt of NHS continuing healthcare continue to be entitled to access to the full range of primary, community, secondary and other health services.
- 108. The PCT responsible for the individual should be determined in accordance with the principles set out in *Who Pays? Establishing the Responsible Commissioner*.¹⁸
- 109. PCTs should ensure that their contracting arrangements with care homes that provide nursing care give clarity on the responsibilities of nurses within the care home and of community nursing services, respectively. No gap in service provision should arise between the two sectors.

Other existing commitments to NHS-funded care

- 110. Apart from a PCT's responsibilities for NHS continuing healthcare and its responsibilities under the Mental Health Act 1983, there may be other circumstances when the NHS is expected to take responsibility for a person's long-term care. One example might be people with learning disabilities, where there may be an existing agreement to fund ongoing care for individuals following the closure of long-stay hospitals or campuses. These responsibilities arise independently of the PCT's responsibility to provide NHS continuing healthcare, and there should be no assumption that these responsibilities equate to eligibility for NHS continuing healthcare or vice versa. Such agreements vary in terms of the commitments they make to fund needs that subsequently arise. Where additional needs do arise, it will be important for the PCT to first check whether there is clarity in such agreements on whether or not they cover responsibilities to meet such needs. If the additional needs fall outside the agreement, PCTs must consider their responsibilities to meet them, in terms both of a PCT's general responsibilities and potential eligibility for NHS continuing healthcare. PCTs should also have arrangements in place for the transfer to the relevant LA of commissioning and funding responsibilities for social care services for people with learning disabilities.¹⁹

18 www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_078466

19 www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Learningdisabilities/DH_090461

Equipment

- 111.** Where individuals in receipt of NHS continuing healthcare require equipment to meet their care needs, there are several routes by which this may be provided:
- a) If the individual is, or will be, supported in a care-home setting, the care home may be required to provide certain equipment as part of regulatory standards or as part of its contract with the PCT. Further details of the regulatory standards can be found on the Care Quality Commission's website at **www.cqc.org.uk**.
 - b) In accordance with the principles set out in paragraphs 102–106, individuals who are entitled to NHS continuing healthcare have an entitlement – on the same basis as other patients – to joint equipment services. PCTs should ensure that the availability to those in receipt of NHS continuing healthcare is taken into account in the planning, commissioning and funding arrangements for these services.
 - c) Some individuals will require bespoke equipment (or other non-bespoke equipment that is not available through routes (a) and (b) above) to meet specific assessed needs identified in their NHS continuing healthcare care plan. PCTs should make appropriate arrangements to meet these needs.

PCTs should ensure that there is clarity about which of the above arrangements is applicable in each individual case.

Links to Other Policies

Links to mental health legislation

- 112.** PCTs and LAs should be familiar with the relevant sections of the Mental Health Act 1983 (as amended).
- 113.** Under section 117 of the Mental Health Act 1983 ('section 117'), PCTs and LAs have a duty to provide after-care services to individuals who have been detained under certain provisions of the Mental Health Act 1983, until such time as they are satisfied that the person is no longer in need of such services. Section 117 is a freestanding duty, and guidance²⁰ advises PCTs and LAs to have in place local policies detailing their respective responsibilities.
- 114.** Responsibility for the provision of section 117 services lies jointly with LAs and the NHS. The specific arrangements for how responsibilities are shared are determined locally. The absence of a local policy agreed between PCTs and LAs on section 117 responsibilities is not a reason for awarding eligibility for NHS continuing healthcare as a substitute for the use of section 117 powers. Some PCTs may use a common budget to fund both section 117 and NHS continuing healthcare, but this does not mean that those in receipt of section 117 support are eligible for NHS continuing healthcare. It is important for PCTs to be clear in each case whether the individual is being funded under section 117, NHS continuing healthcare or any other powers.
- 115.** There are no powers to charge for services provided under section 117, regardless of whether they are provided by the NHS or LAs. Accordingly, the question of whether services should be 'free' NHS services (rather than potentially charged-for social services) does not arise. It is not, therefore, necessary to assess eligibility for NHS continuing healthcare if all the services in question are to be provided as after-care services under section 117.
- 116.** However, a person in receipt of after-care services under section 117 may also have needs for continuing care that are not related to their mental disorder and that may, therefore, not fall within the scope of section 117. An obvious example would be a person who was already receiving continuing care for physical health problems before they were detained under the 1983 Act and whose physical health problems remain on discharge. Where such needs exist, it may be necessary to carry out an

²⁰ www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Healthservicecirculars/DH_4003622

assessment for NHS continuing healthcare that looks at whether the individual has a primary health need on the basis of the needs arising from their physical problems. Any mental health after-care needs that fall within section 117 responsibilities would not be taken into account in considering NHS continuing healthcare eligibility in such circumstances.

Deprivation of liberty safeguards

- 117.** The Mental Capacity Act 2005 contains provisions that apply to a person who lacks capacity and who, in their own best interests, needs to be deprived of their liberty in a care home or hospital, in order for them to receive the necessary care or treatment. The fact that a person who lacks capacity needs to be deprived of his or her liberty in these circumstances does not affect the consideration of whether that person is eligible for NHS continuing healthcare.

Transition from child to adult services

- 118.** The National Framework for NHS continuing healthcare and the supporting guidance and tools should be used to determine what continuing care services people aged 18 years or over should receive from the NHS. A separate policy on continuing care services for those under 18 years has recently been the subject of consultation by the Department.
- 119.** It is important to remember that the legislation and the respective responsibilities of the NHS, social care and other services are different in child and adult services. The term ‘continuing care’ also has different meanings in child and adult services. It is important that young people and their families are helped to understand this and its implications right from the start of transition planning.
- 120.** *Transition: moving on well*²¹ sets out good practice for health professionals and their partners in transition planning for young people with complex health needs or disabilities. *A transition guide for all services*²² explains how all relevant services should work together with a young person to identify how they can best support that person to achieve their desired outcomes. All transition planning for young people should take full account of the approaches set out in these documents.
- 121.** All PCTs should ensure that they are actively involved, with their partners, in the strategic development and oversight of their local transition planning processes, and that their representation includes those who understand and can speak on behalf

21 www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083592

22 www.everychildmatters.gov.uk/_files/TransitionGuide.pdf

of adult NHS continuing healthcare. PCTs should also ensure that adult NHS continuing healthcare is appropriately represented at all transition planning meetings to do with individual young people whose needs suggest that there may be potential eligibility. LAs and PCTs should have systems in place to ensure that appropriate referrals are made whenever either organisation is supporting a young person who, on reaching adulthood, may have a need for services from the other agency.

- 122.** It is desirable and best practice that future entitlement to adult NHS continuing healthcare should be clarified as early as possible in the transition planning process, especially if the young person's needs are likely to remain at a similar level until adulthood.
- 123.** Children's continuing care teams should identify those young people for whom it is likely that adult NHS continuing healthcare will be necessary, and should notify whichever PCT will have responsibility for them as adults. This should occur when a young person reaches the age of 14.
- 124.** This should be followed up by a formal referral for screening at age 16 to the adult NHS continuing healthcare team at the relevant PCT.
- 125.** At the age of 17, eligibility for adult NHS continuing healthcare should be determined in principle by the relevant PCT, so that, wherever applicable, effective packages of care can be commissioned in time for the individual's 18th birthday (or later, if it is agreed that it is more appropriate for responsibility to be transferred then). If needs could change, it may be appropriate to make a provisional decision, and then to recheck it by repeating the process as adulthood approaches.
- 126.** Entitlement to adult NHS continuing healthcare should initially be established using the decision-making process set out in this adult Framework, including the Checklist and the Decision Support Tool. The decision on eligibility should be made using the relevant PCT's usual adult NHS continuing healthcare decision-making processes. The health plans²³ and other assessments and plans developed as part of the transition process will provide key evidence to be considered in the decision-making process. Any entitlement that is identified by means of these processes before a young person reaches adulthood will come into effect on their 18th birthday, subject to any change in their needs.
- 127.** If a young person who receives children's continuing care has been determined by the relevant PCT not to be eligible for a package of adult NHS continuing healthcare

²³ See www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083592

in respect of when they reach the age of 18, they should be advised of their non-eligibility and of their right to request an independent review, on the same basis as NHS continuing healthcare eligibility decisions regarding adults. The PCT should continue to participate in the transition process, in order to ensure an appropriate transfer of responsibilities, including consideration of whether the PCT should be commissioning, funding or providing services towards a joint package of care.

- 128.** Where a young person receives support via a placement outside the PCT's area, it is important that, at an early stage in the transition planning process, there is clear agreement between all the PCTs involved as to who the responsible commissioner presently is, and whether this could potentially change. This should be determined by applying the principles set out in *Who Pays?* All PCTs with current or future responsibilities should be actively represented in the transition planning process. A dispute or lack of clarity over commissioner responsibilities must not result in a lack of appropriate input into the transition process.
- 129.** Even if a young person is not entitled to adult NHS continuing healthcare, they may have certain health needs that are the responsibility of the NHS. In such circumstances, PCTs should continue to play a full role in transition planning for the young person, and should ensure that appropriate arrangements are in place for services that meet these needs to be commissioned or provided. The focus should always be on the individual's desired outcomes and the support needed to achieve these.
- 130.** A key aim is to ensure that a consistent package of support is provided during the years before and after the transition to adulthood. The nature of the package may change because the young person's needs or circumstances change. However, it should not change simply because of the move from children's to adult services or because of a switch in the organisation with commissioning or funding responsibilities. Where change is necessary, it should be carried out in a phased manner, in full consultation with the young person. No services or funding should be withdrawn unless a full assessment has been carried out of the need for adult health and social care services, including the funding responsibilities.
- 131.** The legal responsibilities for child and adult services overlap in certain circumstances. In developing individual transition plans, partners should be clear where such overlaps occur, and the plans should clearly set out who will take responsibility and why. Some local health services for children and young people are only offered up to an age short of adulthood (i.e. 16). PCTs and other partners responsible for children and young people's services should ensure that appropriate services are commissioned to meet needs through to adulthood. A gap in service provision based on age does not mean that adult NHS continuing healthcare services acquire early responsibility. Where

service gaps are identified, PCTs should consider how to address these as part of their strategic commissioning responsibilities.

- 132.** It should be noted that regulations²⁴ state that, in certain circumstances, when a young person in receipt of children’s continuing care reaches adulthood, the care arrangements should be treated as having been made under the adult continuing care provisions. Guidance on the regulations sets out that young people approaching their 18th birthday will require a reassessment of their health and social care needs as part of their transition planning, and that, wherever possible, these young people should continue to receive their healthcare on an unchanged basis until they have been reassessed. It is therefore in the interests of the child/young person and of the PCT and LA to monitor and actively participate in the reviews of those recipients of continuing care who are approaching adulthood.

Personal health budgets and personalisation

- 133.** NHS continuing healthcare cannot presently be provided via direct payment. However, it was announced as part of the NHS Next Stage Review that personal health budgets would be piloted, and *Personal health budgets: first steps* was published in January 2009.²⁵ Three broad approaches are set out there:
- a) **Notional personal budget:** Patients are aware of the treatment options within a budget constraint and of the financial implications of their choices. The NHS underwrites overall costs and retains all contracting and service coordination functions.
 - b) **Real personal budget held by a third party:** Patients are allocated a ‘real budget’, held by an intermediary (e.g. GP, care coordinator, advocate) on their behalf. The intermediary helps the patient choose services within the personal budget and based on the agreed healthcare outcomes.
 - c) **Direct payments for healthcare:** Patients are given cash payments and expected to purchase and manage services themselves, including care coordinators and financial intermediaries. This would be the equivalent of direct payments in social care.

There may be other ways of managing a budget, and it is possible that different elements of a person’s care and support plan lend themselves to being managed differently as part of one care package.

²⁴ The National Health Service (Functions of Strategic Health Authorities and Primary Care Trusts and Administration Arrangements) (England) Regulations 2002, as amended S.I. 2002/2375.

²⁵ www.dh.gov.uk/en/Healthcare/OurNHSourfuture/DH_090018

- 134.** The Department is seeking powers in the Health Bill (currently before Parliament) to allow direct payments to be tested in the pilots, and, if successful, to be introduced more widely. PCTs already have extensive powers to use the first two approaches. The personal health budgets pilot programme will enable PCTs and their partners to be innovative and to explore the opportunities offered by personal health budgets, supported by a focused and rigorous evaluation and as part of a wider learning community that includes everybody who is actively thinking about the issues raised by personal health budgets.
- 135.** PCTs should commission services using models that maximise personalisation and individual control and that reflect the individual's preferences, as far as possible. It is particularly important that this approach should be taken when an individual who was previously in receipt of an LA direct payment begins to receive NHS continuing healthcare; otherwise they may experience a loss of the control they had previously exercised over their care.
- 136.** PCTs and LAs should operate person-centred commissioning and procurement arrangements, so that unnecessary changes of provider or of care package do not take place purely because the responsible commissioner has changed from a PCT to an LA (or vice versa).
- 137.** The above approaches apply both to NHS continuing healthcare and to the NHS elements of a joint package.

Review

- 138.** If the NHS is commissioning, funding or providing any part of the care, a case review should be undertaken no later than three months after the initial eligibility decision, in order to reassess care needs and eligibility for NHS continuing healthcare, and to ensure that those needs are being met. Reviews should then take place annually, as a minimum.
- 139.** If the LA is also responsible for any part of the care, both the PCT and the LA will have a requirement to review needs and the service provided. In such circumstances, it would be beneficial for them to conduct a joint review. Even if all the services are the responsibility of the NHS, it would be beneficial for the review to be held jointly by the NHS and the LA, especially as any decision affecting NHS continuing healthcare eligibility will require input from both sectors. Some cases will require a more frequent case review, in line with clinical judgement and changing needs.
- 140.** When reviewing the need for NHS-funded nursing care, potential eligibility for NHS continuing healthcare must always be considered (using the Checklist), and full consideration should be carried out, where necessary.
- 141.** The outcome of the case review will determine whether the individual's needs have changed, and that will then determine whether the package of care may have to be revised or the funding responsibilities altered. Just because a review has a certain outcome, this does not necessarily indicate that a previous assessment should have had the same outcome, provided the previous assessment was carried out properly and the decision reached on the basis of that assessment was based on sound reasoning.
- 142.** If it is the case that a person was assessed under a previous system as not requiring NHS continuing healthcare, but, following reassessment under the National Framework, is found to be eligible for NHS continuing healthcare, then – assuming that the previous decision under the old system was properly taken (i.e. the criteria at the time were lawful, the criteria were properly applied, there were sound reasons for the decision taken and the process was properly documented) – this should not entitle the person to be reimbursed from the date they were previously refused NHS continuing healthcare. However, if their needs have not changed, it should be considered whether their funding should be backdated to the implementation date of the National Framework (i.e. 1 October 2007).

- 143.** Neither the NHS nor an LA should unilaterally withdraw from an existing funding arrangement without a joint reassessment of the individual, and without first consulting one another and the individual about the proposed change of arrangement. Alternative funding arrangements should first be agreed and put into effect. Any proposed change should be put in writing to the individual by the organisation that is proposing to make such a change. If agreement cannot be reached on the proposed change, the local disputes procedure should be invoked, and current funding arrangements should remain in place until the dispute has been resolved. There is a separate disputes procedure for when the individual disagrees with the decision. Both procedures are set out in paragraphs 146–160 below.
- 144.** The risks and benefits to the individual of a change of location or support (including funding) should be considered carefully before any move or change is confirmed. Neither the PCT nor the LA should unilaterally withdraw from funding of an existing package without appropriate reassessment and agreement by the other body that it accepts funding responsibility. Further details on responsibilities during changes (including approaches to disputes) are set out in Annex E.
- 145.** When reviewing decisions made before implementation of the Framework, PCTs should use the most relevant, lawful criteria. These may, therefore, be pre-National Framework criteria, so long as they are in ‘compliance’ with *Coughlan* and *Grogan*.

Dispute Resolution

Challenges to individual decisions

- 146.** The formal responsibility for informing individuals of the decision about eligibility for NHS continuing healthcare and of their right to request a review lies with that PCT with which the individual is a patient for the purposes of NHS continuing healthcare, in line with *Who Pays?*
- 147.** Whether or not it is considered that the person has a primary health need, the PCT should give clear reasons for its decision. These should set out the basis on which the decision was made.
- 148.** Where a full assessment has been undertaken of potential eligibility using the Decision Support Tool (or by use of the Fast Track Pathway Tool), and a decision has been reached, an individual may apply to the relevant SHA for an independent review of the decision, if they are dissatisfied with:
- a) the procedure followed by the PCT in reaching its decision as to the person's eligibility for NHS continuing healthcare; or
 - b) the application of the criteria of eligibility for NHS continuing healthcare (i.e. the primary health need test)

and the person has been unable to resolve the matter through any local dispute resolution procedure, where following such a procedure would not have caused undue delay.

- 149.** If an individual has been screened out from full consideration following use of the Checklist, they may ask the PCT to reconsider its decision and agree to a full assessment of eligibility (i.e. arrange for the Decision Support Tool to be completed and a decision made on eligibility). The PCT should give this request due consideration, taking account of all the information available, including additional information from the individual or carer. A clear and written response should be given including the individual's (and, where appropriate, their representative's) rights under the NHS complaints procedure if they remain dissatisfied with the position. Individuals who are dissatisfied with the procedure followed by a PCT in reaching a Checklist decision taken on or before 30 September 2009 can appeal to the relevant

SHA, as set out in the NHS Continuing Healthcare (Responsibilities) Directions 2007.²⁶

- 150.** PCTs and SHAs should deal promptly with any request to review decisions about eligibility for either NHS continuing healthcare or NHS-funded nursing care.
- 151.** There are two stages involved in dealing with any requests for a review:
 - a) a local review process at PCT level; and
 - b) a request to the SHA, which may then refer the matter to an independent review panel.
- 152.** Each PCT should agree a local review process, including timescales, which is made publicly available; a copy should be sent to anybody who requests a review of a decision. The local review process may include referral of the case to another PCT for consideration or advice, in order to provide greater patient confidence in the impartiality of the decision making.
- 153.** Once local procedures have been exhausted, the case should be referred to the SHA's independent review panel (IRP) (details in Annex E), which will consider the case and make a recommendation to the PCT. If using local processes would cause undue delay, the SHA has the discretion to agree that the matter should proceed direct to an IRP, without completion of the local process.
- 154.** The key principles for dispute resolution procedures involving NHS continuing healthcare (including both local procedures and independent review panels) are:
 - gathering and scrutiny of all available and appropriate evidence, whether written or oral, including that from the GP, hospital (nursing, medical, mental health, therapies, etc.), community nursing services, care home provider, local authority records, assessments, Checklists, Decision Support Tools, records of deliberations of multidisciplinary teams, panels, etc., as well as any information submitted by the individual concerned;
 - compilation of a robust and accurate identification of the care needs;
 - audit of attempts to gather any records said not to be available;
 - involvement of the individual or their representative as far as possible, including the opportunity for them to contribute and to comment on information at all stages;
 - a full record of deliberations of the review panel, made available to all parties;

²⁶ www.dh.gov.uk/en/Publicationsandstatistics/Legislation/DH_078059

- clear and evidenced written conclusions on the process followed by the NHS body and also on the individual's eligibility for NHS continuing healthcare, together with appropriate recommendations on actions to be taken. This should include the appropriate rationale related to this guidance. The rationale should not be based on:
 - the person's diagnosis;
 - the inputs currently being provided rather than the care needs;
 - the setting of care;
 - the ability of the care provider to manage care;
 - the use (or not) of NHS-employed staff to provide care;
 - the need for/presence of 'specialist staff' in care delivery;
 - the existence of other NHS-funded care; or
 - any other input-related (rather than needs-related) rationale.
- 155.** There should be consistency between the panel deliberations and the recommendation/decision letter.
- 156.** All parties involved should be able to view and comment on all evidence to be considered under the relevant disputes procedure. Where written records or other evidence are requested, the PCT or SHA making the request should ensure that those providing the evidence are aware that it will be made available to those involved in the IRP. Where, in exceptional circumstances, those providing written records place any restrictions on their availability to all parties, the position should be discussed with the chair of the relevant disputes resolution body. The chair should consider the most appropriate way forward to ensure that all parties can play a full and informed role in the process.
- 157.** IRPs have a scrutiny and reviewing role. It is therefore not generally appropriate for any party to be legally represented at IRP hearings, although individuals may wish to be represented by family, advocates, advice services or others in a similar role.
- 158.** The role of the IRP is advisory, but its recommendations should be accepted by the PCT in all but exceptional circumstances.
- 159.** If the original decision is upheld and there is still a challenge, the case should be referred to the Health Service Commissioner (Ombudsman).
- 160.** The individual's rights under the existing NHS and social services complaints procedures and their existing right to refer the case to the Health Service Commissioner remain unaltered by the panel arrangements. In particular, where an individual is dissatisfied with issues other than the process followed or the

application of the criteria, the matter should be considered via the appropriate complaints procedure.

Disputes regarding the responsible body

161. Directions state that PCTs and LAs in each local area should agree a local disputes resolution process to resolve cases where there is a dispute between NHS bodies, or between an LA and a PCT, about eligibility for NHS continuing healthcare and/or about the apportionment of funding in joint funded care/support packages. Disputes should not delay the provision of the care package, and the protocol should make clear how funding will be provided pending resolution of the dispute. Where disputes relate to LAs and PCTs in different geographical areas, the relevant LA and PCT should agree a dispute resolution process to ensure resolution in a robust and timely manner. This should include agreement on how funding will be provided during the dispute, and arrangements for reimbursement to the agencies involved once the dispute is resolved.

The above disputes process could operate in a similar way to the panels established under the Community Care (Delayed Discharges etc.) Act 2003. *Resource pack 2 – Understanding the tools and processes*²⁷ offers advice on developing an NHS continuing healthcare disputes procedure.

162. *Who Pays?* sets out expectations for when there is a dispute between PCTs as to responsibility. Paragraph 2 states: ‘The underlying principle is that there should be no gaps in responsibility – **no treatment should be refused or delayed due to uncertainty or ambiguity as to which PCT is responsible for funding an individual’s healthcare provision.**’ PCTs should agree interim responsibilities for who funds the package until the dispute is resolved.

163. PCTs should also be aware that Annex C of *Who Pays?* also sets out certain circumstances under which the placing PCT retains responsibility for individuals placed outside its area.

164. SHAs should be mindful of their role in resolving disputes, as set out in *Who Pays?*

²⁷ www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_078903

Governance

- 165.** Both PCTs and SHAs have roles in establishing and maintaining governance arrangements for NHS continuing healthcare eligibility processes and commissioning, as they do in other policy areas (see existing guidelines concerning the roles of PCTs and SHAs).
- 166.** PCTs are responsible for:
- a) ensuring consistency in the application of the national policy on eligibility for NHS continuing healthcare;
 - b) promoting awareness of NHS continuing healthcare;
 - c) implementing and maintaining good practice;
 - d) ensuring that quality standards are met and sustained;
 - e) providing training and development opportunities for practitioners;
 - f) identifying and acting on issues arising in the provision of NHS continuing healthcare; and
 - g) informing commissioning arrangements, both on a strategic and an individual basis.
- 167.** PCTs may therefore find it helpful to have in place a system to record the assessments undertaken and their outcomes, and the costs of NHS continuing healthcare packages. It is important that any such system should clearly identify those receiving NHS continuing healthcare as a distinct group from those being supported via joint packages or any other funding routes. This will help PCTs commission care more efficiently and ensure that the data fed back to the Department and the SHA is accurate and consistent.
- 168.** SHA functions include providing strategic leadership and organisational and workforce development, and ensuring that local systems operate effectively and deliver improved performance. SHAs, rather than the Department itself, hold PCTs accountable. SHAs should therefore engage with PCTs to ensure that they discharge the functions for which they are accountable to the Department. In carrying out this role, SHAs should be aware of the range of responsibilities that PCTs hold in relation to NHS continuing healthcare, as detailed in paragraph 166 above.

Annex A: Glossary

Assessment

A process whereby the needs of an individual are identified and their impact on daily living and quality of life is evaluated.

Care

Support provided to individuals to enable them to live as independently as possible, including anything done to help a person live with ill health, disability, physical frailty or a learning difficulty and to participate as fully as possible in social activities. This encompasses health and social care.

Care coordinator

A person who coordinates the assessment and care planning process, where a person needs complex and/or multiple services to support them. Care coordinators are usually the central point of contact with the individual.

Care package

A combination of support and services designed to meet an individual's assessed needs.

Care plan

A document recording the reason why support and services are being provided, what they are, and the outcomes that they seek.

Care planning

A process based on an assessment of an individual's needs that involves working with the individual to identify the level and type of support to meet those needs, and the objectives and potential outcomes that can be achieved.

Carer

A carer looks after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is usually unpaid.

Cognition

The higher mental processes of the brain and the mind, including memory, thinking, judgement, calculation, visual spatial skills, and so on.

Commissioning

The means to secure the best care and the best value for local citizens. It is the process of specifying and procuring services for individuals and the local population, and involves translating their aspirations and needs into services that:

- deliver the best possible health and well-being outcomes, including promoting equality;
- provide the best possible health and social care provision; and
- achieve this with the best use of available resources.

End of life care

Care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms, and provision of psychological, social, spiritual and practical support.

Long-term conditions

Those conditions that cannot, at present, be cured, but can be controlled by medication and other therapies.

Mental capacity

The ability to make a decision about a particular matter at the time the decision needs to be made. The legal definition of a person who lacks capacity is set out in section 2 of the Mental Capacity Act 2005: ‘a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain’.

Mental disorder

Mental disorder is defined in section 1(2) of the Mental Health Act 1983 (as amended by the Mental Health Act 2007) as meaning ‘any disorder or disability of the mind’.

Multidisciplinary

‘Multidisciplinary’ refers to when professionals from different disciplines (such as social work, nursing and occupational therapy) work together to address the holistic needs of their patients/clients, in order to improve delivery of care and reduce fragmentation.

Multidisciplinary assessment

An assessment of an individual’s needs that has actively involved professionals from different disciplines in collecting and evaluating assessment information.

Multidisciplinary team

A team of at least two professionals, usually from both the health and the social care disciplines. It does not refer only to an existing multidisciplinary team, such as an ongoing team based in a hospital ward. It should include those who have an up-to-date knowledge of the individual's needs, potential and aspirations.

Near future

Refers to needs that are reasonably considered by the multidisciplinary team to be likely to arise before the next planned review of the individual.

NHS body

An NHS trust or primary care trust in England.

NHS continuing healthcare

A complete package of ongoing care arranged and funded solely by the NHS, where it has been assessed that the individual's primary need is a health need. It can be provided in any setting. Where a person lives in their own home, it means that the NHS funds all the care and support that is required to meet their assessed health and care needs. Such care may be provided either within or outside the person's home, as appropriate to their assessment and care plan. In care homes, it means that the NHS also makes a contract with the care home and pays the full fees for the person's accommodation, board and care.

Palliative care

The active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.

Personalised

The term used to describe care and services received by a person that are individualised and tailored to their needs.

Registered nurse

A nurse registered with the Nursing and Midwifery Council.

Rehabilitation

A programme of therapy and re-enablement designed to maximise independence and minimise the effects of disability.

Social care

Social care refers to the wide range of services designed to support people to maintain their independence, enable them to play a fuller part in society, protect them in vulnerable

situations and manage complex relationships (*Our Health, Our Care, Our Say: a new direction for community services*, paragraph 1.29). It is provided by statutory and independent organisations, and can be commissioned by local authorities on a means-tested basis, in a variety of settings.

Social services

Social services are provided by 150 local authorities in England. Individually and in partnership with other agencies, they provide a wide range of care and support for people who are deemed to be in need.

Specialist assessment

An assessment undertaken by a clinician or other professional who specialises in a branch of medicine or care, e.g. stroke, cardiac care, bereavement counselling.

Annex B:

The Coughlan Judgment

R v North and East Devon Health Authority, ex parte Pamela Coughlan

Pamela Coughlan was seriously injured in a road traffic accident in 1971. Until 1993, she received NHS care in Newcourt Hospital. When the Exeter Health Authority wished to close that hospital and move Miss Coughlan and other individuals to a new NHS facility at Mardon House, the individuals were promised that Mardon House would be their home for life.

In October 1998, the successor health authority (North and East Devon Health Authority) decided to withdraw services from Mardon House, close that facility, and transfer the care of Miss Coughlan and other disabled individuals to the local authority (LA) social services. Miss Coughlan and the other residents did not wish to move out of Mardon House and argued that the decision to close it was a breach of the promise that it would be their home for life, and was therefore unlawful.

The arguments on the closure of Mardon House raised other legal points about the respective responsibilities of the health service and the social services for nursing care. The Court of Appeal's judgment on this aspect has heavily influenced the development of continuing care policies and the National Framework. The key points in this regard are as follows:

- The NHS does not have sole responsibility for all nursing care. LAs can provide nursing services under section 21 of the National Assistance Act 1948, so long as the nursing care services are capable of being properly classified as part of the social services' responsibilities.
- No precise legal line can be drawn between those nursing services that can be provided by an LA and those that cannot: the distinction between those services that can and cannot be provided by an LA is one of degree, and will depend on a careful appraisal of the facts of an individual case.
- As a very general indication as to the limit of LA provision, if the nursing services are:
 - a) merely incidental or ancillary to the provision of the accommodation that an LA is under a duty to provide, pursuant to section 21; and
 - b) of a nature that an authority whose primary responsibility is to provide social services, can be expected to provide

then such nursing services can be provided under section 21 of the National Assistance Act 1948.

- By virtue of section 21(8) of the National Assistance Act 1948, an LA is also excluded from providing services when the NHS has, in fact, decided to provide those services.
- The services that can appropriately be treated as responsibilities of an LA under section 21 may evolve with the changing standards of society.
- Where a person's primary need is a health need, the responsibility is that of the NHS, even when the individual has been placed in a home by an LA.
- An assessment of whether a person has a primary health need should involve consideration not only of the nature and quality of the services required, but also of the quantity or continuity of such services.
- The Secretary of State's duty under section 3 of (what is now) the National Health Service Act 2006 is limited to providing the services identified, to the extent that he or she considers necessary to meet all reasonable requirements: in exercising his or her judgement, the Secretary of State is entitled to take into account the resources available to him or her and the demands on those resources.
- In respect of Ms Coughlan, her needs were clearly of a scale beyond the scope of LA services.

Annex C:

The Grogan Judgment

R v Bexley NHS Care Trust, ex parte Grogan

Maureen Grogan had multiple sclerosis, dependent oedema with the risk of ulcers breaking out, was doubly incontinent, a wheelchair user requiring two people for transfer, and had some cognitive impairment. After the death of her husband, her health deteriorated and she had a number of falls. Following admission to hospital with a dislocated shoulder, it was decided that she was unable to live independently and she was transferred direct to a care home that provided nursing care.

Subsequent assessments indicated that (under the then local criteria dated December 2002) Mrs Grogan's condition was such that she did not qualify for fully funded NHS continuing healthcare. It was initially determined that she was in the medium band of NHS-funded nursing care. By and large, she remained in this band, although one determination placed her in the high band from April to October 2004. Mrs Grogan argued that the decision to deny her full NHS funding was unlawful, since the eligibility criteria put in place by South East London SHA were contrary to the judgment in the *Coughlan* case. She also submitted that the level of nursing needs identified in the Registered Nursing Care Contribution (RNCC) medium and high bandings (in which she had been placed) indicated a primary need for healthcare that should be met by the NHS.

Key relevant points from the *Grogan* judgment include:

- In assessing whether Mrs Grogan was entitled to NHS continuing healthcare, the care trust did not have in place – and did not apply – criteria which properly identified the test or approach to be followed in deciding whether her primary need was a health need.
- The court identified the fact that there can be an overlap, or a gap, between social care and NHS provision, depending on the test, or tests, applied. The court accepted, as had been submitted by the Secretary of State, that the extent of her duties was governed by NHS legislation, not the upper limits of local authority lawful provision, and that therefore there was a potential in law for a gap between what the Secretary of State provided and those 'health services' that the local authority could 'lawfully' supply.

- If the policy of the Secretary of State was that there should be no gap, then, when applying the primary health need approach, this should be considered against the limits of social services lawful provision, not just by reference to a 'primary health need'.

The trust's decision that Mrs Grogan did not qualify for NHS continuing healthcare was set aside, and the question of her entitlement to NHS continuing healthcare was remitted to the trust for further consideration.

There was no finding, or other indication, that Mrs Grogan in fact met the criteria for NHS continuing healthcare.

Annex D:

Determining the Need for NHS-funded Nursing Care

1. In all cases, individuals should be considered for eligibility for NHS continuing healthcare before a decision is reached about the need for NHS-funded nursing care (NHS-funded nursing care provided by registered nurses) in residential accommodation. In most cases, therefore, the individual will already have been considered for NHS continuing healthcare and will have had an associated assessment, which should provide sufficient information to gauge the need for nursing care in residential accommodation. In certain circumstances, an individual who has been found not to be eligible for NHS continuing healthcare at the Checklist stage may still need an assessment of needs for NHS-funded nursing care. In such cases, an appropriate assessment should be completed. It may, therefore, be appropriate to use the Single Assessment Process (or similar), to ensure that all needs are identified and that the decisions reached are proportionate, reasoned and recorded.
2. Where the local authority (LA) also carries out an assessment of the individual's needs, it may be appropriate for the primary care trust (PCT) to carry out an assessment for NHS-funded nursing care jointly with this process. Where an individual is funding his or her own care needs (apart from NHS-funded nursing care), PCTs should take particular care to ensure that there is clarity on the part of themselves, the relevant LA and the individual as to who is taking responsibility for the assessment, case management and review of the individual's needs on an ongoing basis.
3. The outcome of the above process should provide the PCT with sufficient information to establish a contract with a care home for NHS-funded nursing services, and will trigger the PCT's responsibility to fund the care from a registered nurse through a single rate of payment.

4. Individuals who were in receipt of the high band of NHS-funded nursing care under the three-band system that was in force until 30 September 2007 are entitled to continue on the high band until:
 - a) on review, it is determined that they no longer have any need for nursing care;
 - b) on review, it is determined that their needs have changed, so that under the previous three-band system, they would have moved onto the medium or low bands. In this situation, the individual should be moved onto the single rate;
 - c) they are no longer resident in a care home that provides nursing care;
 - d) they become eligible for NHS continuing healthcare; or
 - e) they die.

Annex E:

Independent Review Panel Procedures

The purpose and scope of independent review panels

1. The revised NHS continuing healthcare directions will require every strategic health authority (SHA) to maintain independent review panels (IRPs).
2. An IRP's key tasks are, at the request of the SHA, to conduct a review of the following:
 - a) the procedure followed by a primary care trust (PCT) in reaching a decision about a person's eligibility for NHS continuing healthcare after the full decision-making process; and
 - b) the application by a PCT of the eligibility criteria for NHS continuing healthcare in making its decision on eligibilityand to make a recommendation to the SHA in the light of its findings on the above matters.
3. An IRP should not proceed if it is discovered that the individual has not previously received a comprehensive assessment of needs and a determination of their eligibility for NHS continuing healthcare, including use of the Decision Support Tool or the Fast Track Pathway Tool, as appropriate. Where an IRP request is received in such circumstances, the SHA should refer the case to the relevant PCT and ask for an assessment of needs and a determination of the individual's eligibility for NHS continuing healthcare to be carried out, if it appears that there may be a need for such care.
4. The IRP procedure does not apply where individuals, their families or any carer wish to challenge:
 - the content of the eligibility criteria;
 - the type and location of any offer of NHS-funded continuing care services;
 - the content of any alternative care package that they have been offered;
 - their treatment or any other aspect of the services they are receiving or have received (this would properly be dealt with through the complaints procedure).
5. The IRP should apply the key principles for dispute resolution processes, as set out in paragraphs 146–160 of the National Framework.

6. Individuals (and their carer and/or representative, where appropriate) should be given clear information about the IRP procedure, the situations it does and does not cover, and how it operates locally. Advocates should be provided where this will support the individual through the review process. SHAs and PCTs should ensure that there are agreed protocols as to how the provision of advocates will operate and the circumstances in which they are to be made available.
7. It is particularly important that, before an IRP is convened, all appropriate steps have been taken by the relevant PCT to resolve the case informally, in discussion with the SHA where necessary. Each organisation should have a named contact, who is the first port of call for queries from partner organisations.
8. If the case cannot be resolved by local resolution (or local resolution will cause undue delay), the individual (or their representative) may ask the appropriate SHA (i.e. the SHA in whose area the decision-making PCT is situated) to arrange an IRP to review the case with regard to the matters listed in paragraph 2 above. Before doing so, the SHA should ensure that none of the circumstances listed at paragraphs 3 and 4 of this annex apply. If any of them are applicable, the SHA should contact the individual and advise them of the appropriate routes for dealing with these matters. If the case nevertheless has some issues that fall within an IRP's responsibilities, the IRP should proceed, but should only deal with the relevant matters.
9. Each SHA should designate an individual to maintain the review procedure and to give advice to IRPs and to the parties involved on the content of the requirements of the National Framework and the associated tools, as well as on any procedural issues. SHAs and PCTs should jointly agree a protocol that identifies responsibilities for obtaining, collecting and circulating information for the IRPs, including all relevant evidence, as set out in paragraph 154 of the Framework.
10. Clear and timely communication is very important. Each SHA should develop and publish timescales for the hearing of IRP cases.
11. The SHA does have the right to decide in any individual case not to convene an IRP. It is expected that such a decision will be confined to those cases where the individual falls well outside the eligibility criteria, or where the case is very clearly not appropriate for the IRP to consider. Before taking such a decision, the SHA should seek the advice of the chair of the IRP, who may require independent clinical advice. In all cases where a decision not to convene an IRP is made, the SHA should give the individual, their family or carer a full written explanation of the basis of its decision, together with a reminder of their rights under the NHS complaints procedure.

12. No individual should be left without appropriate support while they await the outcome of the review. The eligibility decision that has been made is effective while the independent review is awaited. This does not preclude review of eligibility in the meantime by the PCT, using the process set out in paragraphs 138–145, if the individual's needs change or if the time for the next scheduled review of the individual has arrived. Further guidance on responsibilities whilst awaiting the outcome of a request for an independent review will be issued later in 2009.

Establishment and operation of the panels

13. An IRP chair should be selected by the relevant SHA, following an open recruitment process. Those chosen should have a clear understanding of the IRP's purpose and be able to communicate this to the individual, their family and any carers concerned. On the basis of the evidence received and the advice given at the IRP, the chair should be able to determine, in consultation with other IRP members, whether eligibility criteria have been correctly applied. The chair should have the capacity to make balanced decisions in sometimes difficult circumstances, while taking a sympathetic view of the concerns of individuals, their family and any carers.
14. Selection of the right people as chairs – people who are capable of gaining the confidence of all parties – will be a crucial factor in the success of the IRP. Current non-executive directors of SHAs, PCTs or council members should not be considered, but people who have formerly held such a position are eligible. SHAs are strongly advised to involve lay people in the selection process.
15. The appointment of representatives of PCTs and LAs will be on the basis of the nomination of those organisations. They should take account of professional and other skills that are relevant to the work of the IRP. The chair and members of an IRP should receive reasonable expenses.
16. The members of the IRP should meet to consider individual cases. A designated SHA individual should be responsible for ensuring that the relevant information gathered under the protocol referred to in paragraph 9 of this annex is placed before the IRP. The IRP should also have access to the views of key parties involved in the case, including the individual, his or her family and any carer, health and social services staff, and any other relevant bodies or individuals. It will be open to key parties to put their views in writing or to attend. If parties attend, they should be given the opportunity to hear the submissions of other parties and to ask them questions.
17. An individual may have a representative present to speak on his or her behalf if they so choose, or if they are unable or have difficulty in presenting their own views. This role may be undertaken by a relative or carer or advocate acting on the individual's

behalf. The IRP should be satisfied that any person acting on behalf of the individual accurately represents their views, and that the representative's interests or wishes do not conflict with those of the individual. The IRP should respect confidentiality at all times.

18. The IRP will require access to independent clinical advice, which should take account of the range of medical, nursing and therapy needs involved in each case. Such arrangements should avoid any obvious conflicts of interest between the individual clinician(s) giving the advice and the organisation(s) from which the individual has been receiving care. The chair of the relevant IRP should consider in advance of the hearing whether, bearing in mind the nature of the case, the evidence supplied and the role of the clinical adviser set out in paragraph 19 below, there is a need for the panel to access independent clinical advice, and whether this should be in the form of attendance at the hearing or of the clinician supplying written advice.
19. It is the role of the clinical adviser to advise the IRP on the original clinical judgements and on how those judgements relate to the National Framework. It is not the adviser's role to provide a second opinion on the clinical diagnosis, management or prognosis of the individual.
20. An IRP may ask all parties to withdraw while it deliberates and agrees its recommendations. Where appropriate, an IRP may ask an SHA representative and/or the clinical adviser to be present to give advice. The SHA may also be represented in order to keep a record of deliberations.
21. In reaching a view on whether the PCT followed the correct process and whether it correctly applied the eligibility criteria, the range of recommendations made by the IRP for consideration by the SHA and the PCT could include:
 - a) that the case should be reconsidered by the PCT, addressing identified deficiencies in the process used or in the application of the eligibility criteria; or
 - b) that, on the evidence submitted, when compared to the eligibility criteria, the individual should or should not be considered to have a primary health need.
22. A full record should be made of the IRP hearing, including details of those present and their role, the issues and evidence considered, the conclusions and recommendations reached by the IRP, and the reasons for them. A copy of this should be sent by the SHA to all parties.
23. The recommendations of an IRP should be accepted in all but exceptional circumstances.

24. If an SHA decides, in exceptional circumstances, not to accept an IRP recommendation in an individual case, it should explain this in writing to the individual, the PCT and the chair of the IRP, including its reasons for not accepting it.
25. In all cases, the SHA should communicate the outcome of the review, with its reasons, to the individual and the PCT.
26. A PCT should accept the recommendations of the IRP, as forwarded by the SHA, in all but exceptional circumstances. If a PCT decides, in exceptional circumstances, not to accept an IRP recommendation in an individual case, it should explain this in writing to the individual and the SHA, including its reasons. If an SHA or PCT does not accept the recommendations, and if the individual is dissatisfied with this, the matter should be pursued through the NHS complaints procedure.
27. The SHA or PCT, as appropriate, should ensure that the individual is informed in writing of their right to use the NHS complaints procedure in such circumstances.



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