



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

November 2012 (Revised)

Incorporating:

NHS Continuing Healthcare Practice Guidance

NHS Continuing Healthcare Frequently Asked Questions

NHS Continuing Healthcare Refunds Guidance

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

DH INFORMATION READER BOX

Policy	Clinical HR / Workforce Management Planning / Performance	Commissioner Development Provider Development Improvement and Efficiency	Estates IM & T Finance Social Care / Partnership Working
Document Purpose	Policy		
Gateway Reference	18266		
Title	National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care November 2012 (Revised)		
Author	DH		
Publication Date	28 November 2012		
Target Audience	PCT Cluster CEs, NHS Trust CEs, SHA Cluster CEs, Care Trust CEs, Foundation Trust CEs, Medical Directors, Directors of Nursing, Local Authority CEs, Directors of Adult SSs, PCT Cluster Chairs, NHS Trust Board Chairs, Special HA CEs, Directors of Finance, GPs, Emergency Care Leads, Clinical Commissioning Groups, NHS Commissioning Board		
Circulation List	Communications Leads		
Description	This guidance sets out the principles and processes of the National Framework for NHS continuing healthcare and NHS-funded nursing care.		
Cross Ref	NHS Continuing Healthcare Checklist November 2012 (Revised), Decision Support Tool for NHS Continuing Healthcare November 2012 (Revised) and Fast Track Pathway Tool for NHS Continuing Healthcare November 2012 (Revised)		
Superseded Docs	National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care July (Revised) 2009		
Action Required	This is the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care to be used from 1 April 2013		
Timing	For implementation from 1 April 2013		
Contact Details	NHS Continuing Healthcare Policy Team Quarry House Quarry Hill Leeds LS2 7UE http://www.dh.gov.uk/health/2012/11/continuing-healthcare-revisions/		
For Recipient's Use			

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PART 1 THE NATIONAL FRAMEWORK

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 (the National Framework). It reflects the new NHS framework and structures created by the Health and Social Care Act 2012 effective from 1 April 2013. Standing Rules Regulations¹ have been issued under the National Health Service Act 2006², and directions are issued under the Local Authority Social Services Act 1970 in relation to the National Framework.
2. **Transfer of Legal Duties.** Primary Care Trusts (PCTs) have legal duties and responsibilities in relation to NHS Continuing Healthcare until 31 March 2013. From 1 April 2013 these legal duties responsibilities transfer to clinical commissioning groups and, in the case of serving members of the armed forces and their families, or prisoners, to the National Health Service Commissioning Board.
3. **Definitions.** Throughout this guidance:-

'Clinical commissioning group' (CCG) is intended to include any person or body authorised by the CCG to exercise any of its functions on its behalf in relation to NHS continuing healthcare³. Where a CCG delegates such functions it continues to have statutory responsibility and must therefore have suitable governance arrangements in place to satisfy itself that these functions are being discharged in accordance with relevant standing rules and guidance, including the National Framework. The CCG cannot delegate its final decision-making function in relation to eligibility decisions, and remains legally responsible for all eligibility decisions made (in accordance with Standing Rules).

'The National Health Service Commissioning Board' (the Board) is intended to include any person or body authorised by the Board to exercise any of its functions on its behalf in relation to NHS continuing healthcare⁴. Where the Board delegates such functions it continues to have statutory responsibility and must therefore have suitable governance arrangements in place to satisfy itself that these functions are being discharged in accordance with relevant standing rules and guidance, including the National Framework

4. **Scope.** This guidance replaces the previous version of the National Framework, published in July 2009, and comes into force on 1 April 2013. It also incorporates the Practice Guidance, Frequently Asked Questions (FAQs) and Refunds Guidance.

¹ 'The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012'

² National Health Service Act 2006 (c.41), as amended by the Health and Social Care Act 2012 (c. 7).

³ See paragraph 3(3) of Schedule 1A to the National Health Service Act 2006, as inserted by the Health and Social Care Act 2012.

⁴ See paragraph 13 of Schedule A1 to the National Health Service Act 2006, as inserted by the Health and Social Care Act 2012.

5. **Legal framework.** We set out the main responsibilities for the NHS and local authorities (LAs) that are in primary and secondary 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.
6. **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.
7. **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.
8. **Eligibility consideration.** At the heart of the National 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.
9. **Commissioning, care planning and provision.** The Board and CCGs 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.
10. **Access to other NHS-funded services.** Those entitled to NHS continuing healthcare continue to be entitled to access 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.
11. **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. There is an intention to introduce a right to request a personal health budget for people who would benefit from them. People receiving NHS Continuing Healthcare will be the first to have this right from April 2014 subject to the evaluation. This means that all CCGs will have to be ready to implement personal health budgets by April 2014 although they will be able to offer them before this date on a voluntary basis. It is anticipated (at time of writing) that individuals will be given a right to a personal health budget where this will benefit them. It is expected that this will include people receiving NHS continuing healthcare.
12. **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.
13. **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.

14. **Governance.** Both the Board and CCGs have roles in overseeing the process. We explain this in the final section.

The National Framework

Summary

1. This 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.

Actions

2. CCGs and the NHS Commissioning Board (the Board) will assume responsibilities for NHS continuing healthcare from 1 April 2013.
3. The Board will assume commissioning responsibilities for some specified groups of people, for example for prisoners and military personnel. It therefore follows that the Board will have statutory responsibility for commissioning NHS continuing healthcare, where necessary, for those groups for whom it has commissioning responsibility. This will include case coordination, arranging completion of the Decision Support Tool, decision-making, arranging appropriate care packages, providing or ensuring the provision of case management support and monitoring and reviewing the needs of individuals. It will also include reviewing decisions with regards to eligibility where an individual wishes to challenge that decision.
4. Where an application is received for a review of a decision made by the Board, it must ensure that in organising a review of that decision, it makes appropriate arrangements to do so, so as to avoid any conflict of interest.
5. Throughout the Framework where a CCG is referred to, the responsibilities will also apply to the Board in these limited circumstances.
6. CCGs, and where relevant, the Board should consider how the principles and processes in this 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. CCGs should consider how to respond to the commitment in the NHS mandate to the NHS Commissioning Board that patients who could benefit will have the option to hold their own personal health budget.
7. The Board should help facilitate this process. There is a requirement for the Board to operate independent review panels of decisions. Guidance on the operation of panels is set out in this Framework. The Board should also be mindful of their own responsibilities – and those of CCGs – as set out in the ‘Governance’ section below.
8. Local authorities (LAs) should consider this guidance and review whether their current

practice fits with the responsibilities outlined below.

9. Provider organisations should consider the relevant sections of this guidance as they review their current hospital discharge procedures.
10. Provider organisations should also consider their general duty of care to individuals (in the context of any relevant Care Quality Commission requirements) and any contractual obligations in relation to NHS continuing healthcare. In particular they should ensure that individuals who may require a full assessment of eligibility are referred to the CCG, and that accurate records regarding the needs of individuals are made available, as appropriate, in the assessment and review process.
11. CCGs (and where relevant, the Board) and LAs should work together collaboratively when they review existing processes.
12. The Board, CCGs and LAs must comply with their responsibilities, as set out in the Standing Rules Regulations and Directions, as appropriate, to be issued in relation to NHS continuing healthcare.

Background

13. **'NHS continuing healthcare'** means a package of ongoing care that is arranged and funded solely by the NHS where the individual has been found to have a 'primary health need' as set out in this guidance. Such care is provided to an individual aged 18 or over, to meet needs that have arisen as a result of disability, accident or illness. The actual services provided as part of the 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.
14. **'NHS-funded nursing care'** is the funding provided by the NHS to homes providing nursing to support the provision of nursing care by a registered nurse. Since 2007 NHS-funded nursing care has been based on a single band rate. 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.
15. Individuals who need ongoing care/support may require services arranged by CCGs and/or LAs. CCGs and LAs therefore have a responsibility to ensure that the assessment of eligibility for care/support 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 commissioning services or by part-funding the package of support. Where a package of support is commissioned or funded by both an LA and a CCG, this is known as a 'joint package' of care (see paragraphs 113 -117). 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 the CCG and the LA both contributing to the cost of the care package, or the CCG commissioning 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.
16. Personal health budgets give patients real control and choice over how to meet their health

and care needs. Over 60 sites took part in a pilot programme to understand how they can benefit those who need them the most, and how best they should be implemented. The evaluation of the pilot was completed in Autumn 2012⁵. A personal health budget is not new money, but rather enables people to use funding in different ways, ways that work for them. More information on personal health budgets including a toolkit which brings together learning from pilot and good practice examples is available⁶

17. This guidance is based on statutory responsibilities, case law, input from the Parliamentary and Health Service Ombudsman, and comments received from stakeholders. 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 (DST) and the Fast Track Pathway Tool. Separate notes are attached to the tools themselves to explain how they should be applied.

Legal Framework

Legislation

18. Primary legislation governing the health service does not use or define the expressions 'continuing care', 'NHS continuing healthcare' or 'primary health need'. However, section 1 of the National Health Service Act 2006 (the 2006 Act) (as amended by the Health and Social Care Act 2012) requires the Secretary of State to continue the promotion in England of a comprehensive health service, designed to secure improvement:

- a) in the physical and mental health of the people of England; and
- b) in the prevention, diagnosis and treatment of illness.

Section 1A of the 2006 Act further requires the Secretary of State to exercise these functions with a view to securing continuous improvement in the quality of services provided to individuals for or in connection with:

- (a) the prevention, diagnosis or treatment of illness, or
- (b) the protection or improvement of public health

19. Section 1B of the 2006 Act imposes a duty on the Secretary of State to have regard to the NHS Constitution.
20. Section 1C of the 2006 Act states that, in exercising functions in relation to the health service, the Secretary of State must have regard to the need to reduce inequalities between the people of England with respect to the benefits that they can obtain from the health service.

⁵ www.phb.org.uk

⁶ www.personalhealthbudgets.dh.gov.uk

21. In addition:

Section 1H of the 2006 Act establishes the Board, an independent body, which will hold CCGs to account for the quality of services they commission, the outcomes they achieved for patients and for their financial performance. The Board also has the power to intervene where there is evidence that CCGs are failing or are likely to fail to fulfil their functions. The specific functions of the Board, such as commissioning specialised services, are conferred elsewhere 2006 Act. Like the Secretary of State, the Board is subject to the duty to promote the comprehensive health service (other than in respect of those services falling within the public health functions of the Secretary of State or local authorities).

Subsection (3) of section 1H also provides that, in order to fulfil this general duty, the Board has two specific functions:

- (a) it must commission services in accordance with the 2006 Act. The services which the Board may be required to commission are described in section 3B of the 2006 Act and include services which can be more effectively commissioned at national level, or which it would be inappropriate or impractical for CCGs to commission. Those services include prison health services and health services for the members of the armed forces and their families; and
- (b) when exercising functions in relation to CCGs (for example, when issuing commissioning guidance)

Section 3 of the 2006 Act requires CCGs to provide a range of services, to such an extent as they consider necessary to meet all reasonable requirements. These services must include, amongst other categories, 'such other services or facilities for the prevention of illness, the care of persons suffering from illness⁷, and the after-care of persons who have suffered from illness as the group considers are appropriate as part of the health service' (section 3 (1)(e) of the 2006 Act).

22. In summary, under the amended 2006 Act, the Board will, from 1 April 2013, be responsible for ensuring that the NHS delivers better outcomes for patients within its available resources by supporting, developing and performance managing an effective system of CCGs. The Board will also take responsibility for commissioning services that can only be provided efficiently and effectively at a national or a regional level.
23. The Secretary of State for Health will remain accountable for the NHS. The amendments to the 2006 Act do not change the Secretary of State's core duty to promote a comprehensive health service, which dates back to the founding NHS Act of 1946. The Secretary of State must bear this duty in mind whenever he exercises any of his functions.
24. 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

⁷ In the context of the 2006 Act, "illness" includes mental disorder within the meaning of the Mental Health Act 1983 (c. 20) and any injury or disability requiring medical or dental treatment or nursing (NHS Act 2006, section 275(1))

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 CCG if, in carrying out the assessment, it becomes apparent to the authority that the person has needs which may fall under the 2006 Act, and invite the CCG to assist in making the assessment (see section 47(3) of the National Health Service and Community Care Act 1990).

25. 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 in order for the LA to then fulfil its responsibilities.
26. 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 2006 Act. 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 30 below for more on the *Coughlan* judgement):

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 2006 Act. Such health services would not therefore include services which the Secretary of State legitimately decided under section 3(1) of the 2006 Act it was not necessary for the NHS to provide.
27. 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 2006 Act and so excludes only those services that must, as a matter of law, be provided under the 2006 Act.
28. 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'.
29. Deciding on the balance between LA and NHS responsibilities with respect to continuing care has been the subject of key court judgments.

Case law

30. 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 set out 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.
31. 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*.
32. Eligibility for NHS continuing healthcare must always be considered, and a decision made and recorded (either at the Checklist or DST stage), 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.

Practice Guidance Notes – see Part 2 of document.

Page 50: Is there an authoritative definition of ‘beyond the responsibility of the Local authority’?

Page 50: What is the difference between a healthcare need and a social care need?

Primary Health Need

33. To assist in deciding which treatment and other health services it is appropriate for the NHS to provide under the 2006 Act, 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 has been

assessed to have a 'primary 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 health and social care needs – including accommodation, if that is part of the overall need.

34. 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 their eligibility criteria for adult social care⁸) 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
35. There are certain limitations to this test, which was originally indicated in Coughlan: neither the CCG, nor the LA can dictate what the other agency should provide. 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

⁸ See *Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care. Guidance on Eligibility Criteria for Adult Social Care, England 2010*
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113155.pdf

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.

36. 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.
37. 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. CCGs 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 2012⁹.
38. 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 (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 97 - 107.
 - 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 35 may well apply to those people approaching the end of their lives, and eligibility should always be considered.
39. Good practice in end of life care is currently supported through the National End of Life Care Programme¹⁰, which works with health and social care services across all sectors

⁹ <http://www.dh.gov.uk/health/2012/11/continuing-healthcare-revisions/>

¹⁰ <http://www.endoflifecareforadults.nhs.uk/>

in England to improve end of life care for adults by implementing the Department of Health's End of Life Care Strategy¹¹. The principles of the Strategy should be reflected in all NHS continuing healthcare cases that involve individuals with an end of life condition.

40. 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 (DST). The DST supports practitioners in identifying the individual's needs, which, combined with the practitioners' skills, knowledge 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 judgements.
41. Further details about the DST and its application are set out below (paragraphs 77 - 89) and in the notes accompanying the tool. Before using the DST, 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.

Practice Guidance Note – see Part 2 of document.

*Page 51: **What is a primary health need?***

Core Values and Principles

42. 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, and how their personal information is shared, should be documented and taken into account, along with the risks of different types of provision and fairness of access to resources.
43. 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). The Board and CCGs are responsible for ensuring that discrimination does not occur and should use effective auditing to monitor this matter (see the section on 'Governance' below).
44. Assessments of eligibility for NHS continuing healthcare and NHS-funded nursing care

¹¹ <http://www.dh.gov.uk/health/2011/07/end-of-life-care-strategy/>

should be organised so that the individual being assessed and their representative¹² 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.

Practice Guidance Note – see Part 2 of document.

Page 53: What are the key elements of a ‘person-centred’ approach in NHS continuing healthcare?

Consent

45. 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.
46. 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, and for personal information to be shared between different organisations involved in their care. It should also be noted that individuals may withdraw their consent at any time in the process.
47. 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 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 CCG 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.

¹²In this Framework the term **representative** is intended to include any friend, unpaid carer or family member who is supporting the individual in the process as well as anyone acting in a more formal capacity (e.g. welfare deputy or power of attorney, or an organisation representing the individual).

Practice Guidance Notes – see Part 2 of document.

Page 55: What specific guidance is there in relation to dealing with confidentiality?

Page 58: What happens if an individual with mental capacity refuses to give consent to being considered for NHS continuing healthcare eligibility?

Capacity

48. 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 2005¹³ and the associated code of practice¹⁴. CCGs should be particularly aware of the five principles of the Act:
- **A presumption of capacity:** A person must be assumed to have capacity unless it is established that they lack capacity.
 - **Individuals being supported to make their own decisions:** A person is not to be treated as unable to make a decision unless all practicable steps to help him or her to do so have been taken without success.
 - **Unwise decisions:** A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
 - **Best interests:** An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his or her best interests.
 - **Least restrictive option:** Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.
49. It is important to be aware that just because an individual may have difficulty in expressing their views or understanding some information, this does not in itself mean that they lack capacity. Appropriate support and adjustments should be made available to the person¹⁵, in compliance with the Mental Capacity Act 2005 and with disability discrimination legislation.
50. If the person lacks the mental capacity to either give or refuse consent to the use of the Checklist, a 'best interests' decision, taking the individual's previously expressed views into account, should be taken (and recorded) as to whether or not to proceed with assessment of eligibility for NHS continuing healthcare. The person leading the assessment is responsible for making this decision and 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.

¹³ http://www.legislation.gov.uk/ukpga/2005/9/pdfs/ukpga_20050009_en.pdf

¹⁴ <http://www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/mca-code-practice-0509.pdf>

¹⁵ Section 1(3) and Section 3(2) Mental Capacity Act 2005

51. Where a 'best interests' decision needs to be made, the 'decision-maker' must consult¹⁶ with any relevant third party who has a genuine interest in the person's welfare. This will normally include family and friends. However, third parties should not receive information where the patient has previously made it clear that they do not consent to information being shared with them.

Practice Guidance Note – see Part 2 of document.

Page 58: *What if there are concerns that the individual may lack capacity to consent to the completion of a Checklist/DST?*

Advocacy

52. 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. An IMCA must be instructed/consulted where an individual lacks capacity in relation to the relevant decision and has no family or friends that are available (or appropriate) for consultation on their behalf.
53. 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 to help to ensure that their views and wishes are represented and taken into account. CCGs 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 or 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 CCGs) to act as an advocate on their behalf.

Practice Guidance Notes – see Part 2 of document.

Page 60: *When is it appropriate to involve an Independent Mental Capacity Advocate (IMCA)?*

Page 60: *Whose responsibility is it to provide advocacy for individuals going through the eligibility decision-making process?*

Page 61: *Do individuals need to have legal representation during the NHS*

¹⁶ Section 4(7) Mental Capacity Act 2005

continuing healthcare eligibility process?

Carers

54. CCGs 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 the CCG 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. CCGs and LAs should be mindful of the approaches set out in the national strategy for carers with reference to *Recognised, valued and supported: Next steps for the Carers Strategy*¹⁷.

Other eligibility issues

55. Eligibility for NHS continuing healthcare is based on an individual's assessed needs. The diagnosis of a particular disease or condition is not in itself a determinant of eligibility for NHS continuing healthcare.
56. NHS continuing healthcare may be provided 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, such that the active management of this need is reduced or no longer required, will this have a bearing on NHS continuing healthcare eligibility.
57. 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.
58. The reasons given for a decision on eligibility should NOT be based on the:
- a. person's diagnosis;
 - b. setting of care;
 - c. ability of the care provider to manage care;
 - d. use (or not) of NHS-employed staff to provide care;
 - e. need for/presence of 'specialist staff' in care delivery;
 - f. the fact that a need is well managed;
 - g. the existence of other NHS-funded care; or

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http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_122393.pdf

- h. any other input-related (rather than needs-related) rationale.
59. 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.

Practice Guidance Note – see Part 2 of document.

*Page 61: **How should the well-managed need principle be applied?***

Assessments

60. 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. It is important that those contributing to the comprehensive assessment have the relevant skills and knowledge. It is best practice that where the individual concerned has, for example a learning disability, or a brain injury, someone with specialist knowledge of this client group is involved in the assessment process.
61. The comprehensive assessment of an individual's care and support 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, CCGs 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.

Practice Guidance Note – see Part 2 of document.

*Page 62: **Dealing openly with issues of risk***

Eligibility Consideration

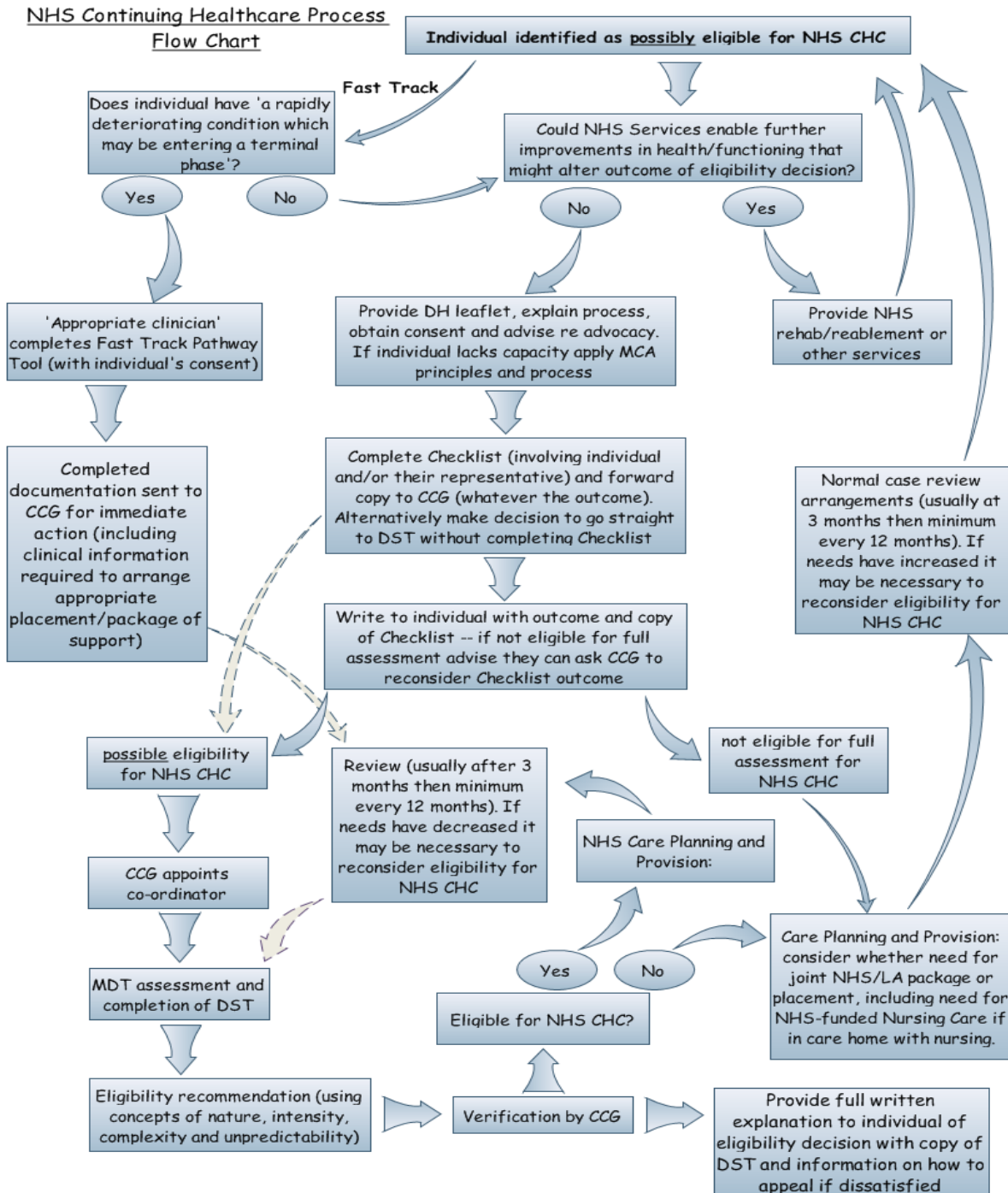


Figure 1: Overall process for determining eligibility for NHS continuing healthcare (NHS CHC) and the NHS elements of joint packages of care (including NHS-funded nursing care). Please see main text for explanation.

Hospital Discharge

62. In a hospital setting, before an NHS trust, NHS foundation trust or other provider organisation gives notice of an individual's case to an LA, in accordance 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.
63. CCGs 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 responsibilities are to be exercised in relation to delayed discharge and NHS continuing healthcare, including 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 NHS continuing healthcare, for full assessment of eligibility to then take place.
64. 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.
65. 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.
66. 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.
67. Whenever an individual outside a hospital setting is having their health or social needs assessed or reviewed by a CCG 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

68. 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 97 - 107) or for other NHS-funded services to be provided (see paragraph 65). 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.
69. Standing Rules Regulations make it clear that if the CCG is to use any screening tool, that tool must be the NHS Continuing Healthcare Checklist. They may, if they wish, directly move to a full MDT assessment for an individual without using a Checklist. However, a CCG cannot use a different tool or method for screening for NHS continuing healthcare.
70. Standing Rules Regulations require a CCG to take reasonable steps to ensure that individuals are assessed for NHS continuing healthcare in all cases where it appears that there may be a need for such care.
71. Before the Checklist is applied, it is necessary to ensure that the individual and (where appropriate) their representative understand that the Checklist does not necessarily indicate that the individual will be eligible for NHS continuing healthcare – only that they are entitled to consideration for eligibility.
72. 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. However, there may also be circumstances where a full assessment for NHS continuing healthcare is appropriate even though the individual does not apparently meet the indicated threshold set out at paragraph 21 of the Checklist user notes.
73. A nurse, doctor, other qualified healthcare professional or social care professional 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 77 - 89).
74. 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 and then to carry out a full assessment of eligibility at a later stage. This should be recorded. The relevant CCG 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 relevant CCG retains responsibility for funding appropriate care.
75. No individual should be left without appropriate support while they await the outcome of

the decision-making process.

76. 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 CCG to reconsider the decision. The CCG 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 as enshrined in the NHS Constitution.

Practice Guidance Notes – see Part 2 of document.

Screening for NHS Continuing Healthcare – the Use of the Checklist Tool

Page 63: How does NHS continuing healthcare fit with hospital discharge procedures?

Page 64: How does NHS continuing healthcare link with intermediate care?

Page 65: What is the NHS continuing healthcare Checklist?

Page 65: Does everyone need to have a Checklist completed?

Page 66: Who can complete a Checklist?

Page 66: When should a Checklist be completed if the individual is in hospital?

Page 67: When should the Checklist be completed if the individual is in the community or in a care setting other than hospital?

Page 67: Who needs to be present when a Checklist is completed?

Page 68: What information needs to be given to the individual when completing a Checklist?

Page 68: What should happen once the Checklist has been completed?

Page 69: What evidence is required for completion of the Checklist?

Page 69: Can registered nurses in care home settings complete a Checklist Tool?

Page 69: Can someone self-refer by completing a Checklist themselves?

Decision Support Tool

77. 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 CCG has responsibility for coordinating the whole process until the decision on funding has been made and a care plan agreed. The CCG should identify an individual (or individuals) to carry out this coordination role, which is pivotal to the effective management of the assessment and decision-making process. By mutual agreement, the coordinator may either be a CCG member of staff or be from an external organisation.
78. 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).
79. 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.
80. 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, relative 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 specialist assessments, and should make referrals for other specialist assessments whenever that is appropriate in light of the individual's care needs.
81. 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.
82. The multidisciplinary assessment should be in such a format that it can also be used to assist the CCG and LA to meet care needs regardless of eligibility for NHS continuing healthcare.
83. 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. Standing Rules¹⁸ require that, as far as is reasonably practicable, the CCG 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 CCG, 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

¹⁸ National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012

advice and assistance to the CCG. LAs should also advise the CCG 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.

84. 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, irrespective of their client group or diagnosis. 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.
85. 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.

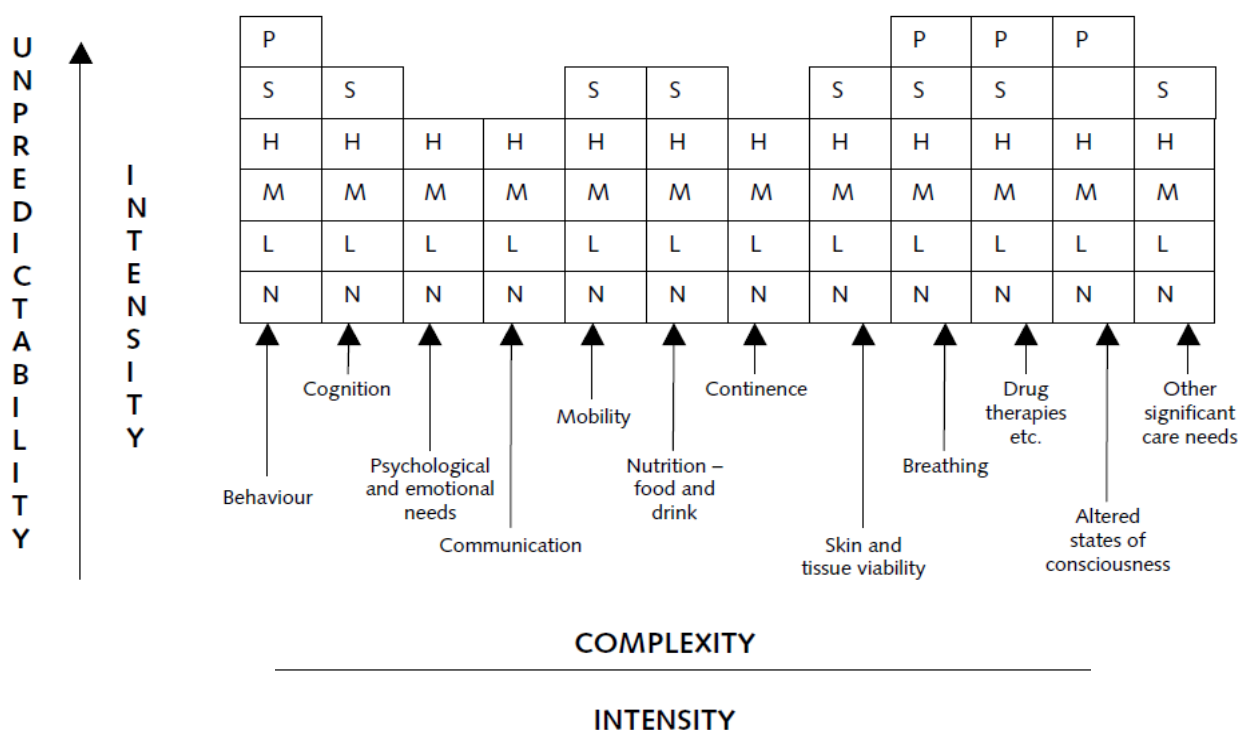


Figure 2: How the domains help build up a picture of complexity, intensity and unpredictability. Within the 12 care domains, N = No, L = Low, M = Moderate, H = High, S = Severe and P = Priority.

86. 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.
87. The multidisciplinary team should use the Decision Support Tool 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.
88. 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.
89. Once the multidisciplinary team has reached agreement, it should make a recommendation to the Board or a CCG on eligibility.

Practice Guidance Notes – see part 2 of document.

Multidisciplinary Assessment, Completion of the DST and Making Recommendations

Page 70: What is the role of the NHS continuing healthcare coordinator?

Page 71: Why isn't the DST an assessment tool?

Page 71: What are the elements of a good multidisciplinary assessment?

Page 73: Potential Sources of Information/Evidence:

Page 74: What is a Multidisciplinary team in the context of NHS continuing healthcare?

Page 75: What happens if the coordinator is unable to engage relevant professionals to attend an MDT meeting?

Page 75: Where should an MDT meeting take place?

Page 76: What process should be used by MDTs to ensure consistency when completing the DST?

Page 77: What is proportionate and reasonable in terms of evidence required to support domain levels and the recommendation in a DST?

Page 77: What happens if MDT members cannot agree on the levels within the domains of the DST?

Page 78: What happens if the individual concerned or their representative disagrees with any domain level when the DST is completed?

Page 78: What does the DST recommendation need to cover?

Page 80: How does the Decision Support Tool (DST) and primary health need eligibility test apply to people with learning disabilities?

Decision-making

90. CCGs 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.

91. The CCG may choose to 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.
92. The CCG 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, the CCG 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.
93. CCGs 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. The final eligibility decision should be independent of budgetary constraints, and finance officers should not be part of a decision-making panel.
94. As part of their responsibility to ensure consistent application of the National Framework, a CCG 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.
95. The time that elapses between the Checklist (or, where no Checklist is used, other notification of potential eligibility) being received by the CCG 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. The CCG 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 65 above.
96. 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.

*Practice Guidance Notes – see part 2 of document.
Eligibility and Panel Processes*

Page 81: If a CCG uses a panel as part of the decision-making process what should its function be and how should it operate?

Page 82: What should the role of the CCG decision-making process be?

Page 82: What are the 'exceptional circumstances' under which a CCG or panel

might not accept an MDT recommendation regarding eligibility for NHS continuing healthcare?

Page 83: How should decisions be communicated to the individual/representative?

Page 83: If a person dies whilst awaiting a decision on NHS continuing healthcare eligibility, should a decision still be made in respect of eligibility for the period before their death?

Fast Track Tool

97. Individuals with a rapidly deteriorating condition that may be entering a terminal phase, may require 'fast tracking' for immediate provision of NHS continuing healthcare. The Fast Track Tool should be completed by an appropriate clinician, who should give the reasons why the person meets the criterion required for the fast-tracking decision. 'Appropriate clinicians' are those persons who are, pursuant to the 2006 Act, 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.
98. 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 2006 Act. 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 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 Tool.
99. The completed Fast Track 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 appropriate clinician to make a decision based on the needs of the person.
100. Where a recommendation is made for an urgent package of care via the fast-track process, this should be accepted and actioned immediately by the CCG. It is not appropriate for individuals to experience delay in the delivery of their care package while concerns over the use of the Fast Track Tool are resolved. CCGs should carefully monitor use of the tool and raise any specific concerns with clinicians, teams and organisations. Such concerns should be treated as a separate matter from the task of arranging for service provision in the individual case.
101. 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 139 - 144 . The review should include completion of a Decision Support Tool by a multidisciplinary team,

including them making a recommendation on eligibility.

102. The purpose of the Fast Track Tool is to ensure that individuals with a rapidly deteriorating condition that may be entering a terminal phase are supported in their preferred place of care as quickly as possible. This overall process including how personal information will be shared between different organisations and healthcare professionals involved in delivering care, 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.
103. Where an individual who is receiving services from use of the Fast Track Tool is expected to die in the very near future, the CCG should continue to take responsibility for the care package until the end of life.
104. 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 Tool when individuals satisfy the criteria for its use.
105. 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.
106. In end of life cases, CCGs and LAs should take particular account of paragraphs 169 - 171 regarding person-centred commissioning and procurement arrangements.
107. 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 Strategy¹⁹, with full account being taken of patient preferences, including those set out in advance care plans.

Practice Guidance Notes – see part 2 of document.

The Fast Track Pathway Tool for NHS Continuing Healthcare

Page 83: In a Fast Track case is it the PCT or the 'appropriate clinician' who decides that the individual has a primary health need?

Page 84: Who can complete the Fast Track Pathway Tool?

Page 84: What is the relationship between the Fast Track Pathway Tool and the Checklist/Decision Support Tool?

¹⁹ <http://www.endoflifecareforadults.nhs.uk/publications/eolc-strategy>

Page 84: Do individuals need to consent to a Fast Track Pathway Tool being completed?

Page 85: Is the use of the Fast Track Pathway Tool dependent on specific timescales in relation to end of life care?

Page 85: What evidence is required when completing the Fast Track Pathway Tool?

Page 86: Can a CCG refuse to accept a completed Fast Track Pathway Tool?

Page 87: What actions can CCGs take if the Fast Track Pathway Tool is being used inappropriately?

Page 87: How quickly could a hospital discharge take place following the completion of the Fast Track Tool?

Page 87: What settings can a Fast Track Pathway Tool be used in?

Page 88: Does the Fast Track tool need to be completed if the individual is already receiving a care package which could still meet their needs?

Page 88: Should individuals receiving care via the Fast Track Pathway Tool have their eligibility for NHS continuing healthcare reviewed?

Page 89: Can the national tools be changed?

Page 89: Why is it important to complete the equality monitoring forms with the tools?

Commissioning, care planning and case management

108. Where an individual is eligible for NHS continuing healthcare, the CCG is responsible for care planning, commissioning services and for case management. It is the responsibility of the CCG to plan strategically, specify outcomes and procure services, to 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. The services commissioned must include ongoing case management for all those entitled to NHS continuing healthcare, as well as for the NHS elements of joint packages, including review and/or reassessment of the individual's needs.
109. 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 the CCG. CCGs should ensure that there is clarity on

the respective responsibilities of commissioners and providers with regard to NHS continuing healthcare.

110. CCGs should take a strategic as well as an individual approach to fulfilling their NHS continuing healthcare commissioning responsibilities. CCGs 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, CCGs and LAs should work in partnership, and share information (where reasonable) to enable them to commission the most appropriate packages of care for their populations.
111. Many individuals in receipt of NHS continuing healthcare and joint care packages will have long-term conditions. CCGs and LAs should take into account the policy set out in *Supporting People with Long Term Conditions: Commissioning Personalised Care Planning*²⁰. 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. The individual and personalised approaches described in *Valuing People Now* 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.

See also paragraphs 166 - 171 below regarding commissioning and personalisation.

Other existing commitments to NHS-funded care

112. Apart from a CCG's responsibilities for NHS continuing healthcare and their respective 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 a CCG'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 CCG 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, CCGs must consider their responsibilities to meet them, in terms both of the CCG's general responsibilities and potential eligibility for NHS continuing healthcare.

Joint packages of health and social care services

113. 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).

²⁰ http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093360.pdf

114. There will be some individuals who, although they are not entitled to NHS continuing healthcare (because ‘taken as a whole’ their needs are not beyond the powers of a local authority to meet), but nonetheless have some specific 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. CCGs should work in partnership with their LA colleagues to agree their respective responsibilities in a joint package of care, including which party will take the lead commissioning role.
115. 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/reablement 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.
116. According to each LA’s eligibility threshold 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 30 above (see also Annex B).
117. 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 can provide some health services, subject to the legal limitations set out in paragraphs 30 above.

Practice Guidance Notes – see part 2 of document

*Page 89: **What are joint packages of care?***

*Page 90: **Practice Example – Joint Package of Care***

*Page 91: **Does NHS-funded Nursing Care cover the entire cost of a person’s nursing needs?***

*Page 92: **In a joint package does the DST define which elements are the responsibility of the NHS and which are the responsibility of social services?***

*Page 92: **How does NHS-funded nursing care affect other funding for the care package such as from local authorities?***

*Page 92: **Is there a national tool for assessing NHS-funded nursing care?***

Links to other Policies

Links to mental health legislation

118. CCGs and LAs should be familiar with the relevant sections of the Mental Health Act 1983 (as amended).
119. Under section 117 of the Mental Health Act 1983 ('section 117'), CCGs 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 to provide after-care services for needs arising from their mental disorder and CCGs and LAs should have in place local policies detailing their respective responsibilities, including funding arrangements.
120. Responsibility for the provision of section 117 services lies jointly with LAs and the NHS. Where a patient is eligible for services under section 117 these should be provided under section 117 and not under NHS continuing healthcare. It is important for CCGs to be clear in each case whether the individual's needs (or in some cases which elements of the individual's needs) are being funded under section 117, NHS continuing healthcare or any other powers, irrespective of which budget is used to fund those services.
121. 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.
122. However, a person in receipt of after-care services under section 117 may also have ongoing care/support needs that are not related to their mental disorder and that may, therefore, not fall within the scope of section 117. Also a person may be receiving services under section 117 and then develop separate physical health needs (e.g. through a stroke) which may then trigger the need to consider NHS continuing healthcare only in relation to these separate needs, bearing in mind that NHS continuing healthcare should not be used to meet section 117 needs. Where an individual in receipt of section 117 services develops physical care needs resulting in a rapidly deteriorating condition which may be entering a terminal phase, consideration should be given to the use of the Fast Track Pathway Tool.

Practice Guidance Notes – see part 2 of document.

Page 93: What is the relationship between NHS continuing healthcare and section 117 after-care under the Mental Health Act?

Page 93: Is there any additional guidance on the relationship between NHS

continuing healthcare and the Mental Health Act?

Page 93: Do we make NHS-funded Nursing Care payments for section 117 patients placed in nursing homes?

Deprivation of Liberty Safeguards

123. The Mental Capacity Act 2005 contains provisions that apply to a person who lacks capacity and who, in their 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, in itself, preclude or require consideration of whether that person is eligible for NHS continuing healthcare.

Transition from child to adult services

124. The National Framework for NHS continuing healthcare and the supporting guidance and tools should be used to determine what ongoing care services people aged 18 years or over should receive from the NHS.
125. 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.
126. '*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.
127. CCGs 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 of adult NHS continuing healthcare. CCGs 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. CCGs and LAs 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.

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

²² http://www.transitioninfonetwork.org.uk/PDF/Transition_Guide_For_All_Services.pdf

128. 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.
129. Children's services should identify those young people for whom it is likely that adult NHS continuing healthcare will be necessary, and should notify whichever CCG will have responsibility for them as adults. This should occur when a young person reaches the age of 14.
130. This should be followed up by a formal referral for screening at age 16 to the adult NHS continuing healthcare team at the relevant CCG.
131. At the age of 17, eligibility for adult NHS continuing healthcare should be determined in principle by the relevant CCG, 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). In order to do this staff from adult services (who are familiar with the Adult Framework) will need to be involved in both the assessment and care planning to ensure smooth transition to adult services. If needs are likely to change, it may be appropriate to make a provisional decision, and then to recheck it by repeating the process as adulthood approaches.
132. 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 CCG's usual adult NHS continuing healthcare decision-making processes. The health plans 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.
133. If a young person who receives children's continuing care has been determined by the relevant CCG not to be eligible for a package of adult NHS continuing healthcare 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 CCG should continue to participate in the transition process, in order to ensure an appropriate transfer of responsibilities, including consideration of whether they should be commissioning, funding or providing services towards a joint package of care.
134. Where a young person receives support via a placement outside the CCG's area, it is important that, at an early stage in the transition planning process, there is clear agreement between the CCGs 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 'responsible commissioner' guidance (currently *Who Pays? Establishing the Responsible Commissioner*²³) All parties 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

²³ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_078466

appropriate input into the transition process.

135. 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, CCGs 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.
136. 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 change in the organisation with commissioning or funding responsibilities. Where change is necessary, it should be carried out in a planned manner, in full consultation with the young person. No services or funding should be unilaterally withdrawn unless a full joint health and social care assessment has been carried out and alternative funding arrangements have been put in place.
137. 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). CCGs 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, CCGs should consider how to address these as part of their strategic commissioning responsibilities.
138. 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 CCG and LA to monitor and actively participate in the reviews of those recipients of continuing care who are approaching adulthood.

Review

139. 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

²⁴ National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012

ensure that those needs are being met. Reviews should then take place annually, as a minimum. It is expected that any previously completed DST will normally be available at the review and each of the domains and previously assessed need levels considered by the reviewer. This should be done in consultation with the person being reviewed and any other relevant people who know the person who are present at the review. However, the focus of the review should not just be on whether the individual remains eligible for NHS continuing healthcare but on whether needs are being met and whether the package of care remains appropriate.

140. If the LA is also responsible for any part of the care, both the CCG 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 where practicable. If all the services are the responsibility of the NHS, it may be beneficial for the review to be held jointly by the NHS and the LA where there is an indication of a need for a social care assessment as part of the review process. Some cases will require a more frequent case review, in line with clinical judgement and changing needs.
141. 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.
142. 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.
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. It is essential that alternative funding arrangements are agreed and put into effect before any withdrawal of existing funding, in order to ensure continuity of care. Any proposed change should be put in writing to the individual by the organisation that is proposing to make such a change. If agreement between the LA and NHS cannot be reached on the proposed change, the local disputes procedure should be invoked, and current funding and care management responsibilities 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 145 - 165 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 CCG nor the LA should unilaterally withdraw from funding of an existing package until there has been appropriate reassessment and agreement on future funding responsibilities and any alternative funding arrangements have been put into effect. Further details on responsibilities during changes (including approaches to disputes) are set out in Annex F.

Practice Guidance Note – see part 2 of document.

Page 94: Is it necessary to complete a full Checklist and Decision Support Tool (DST) when carrying out a routine / annual review of NHS-funded Nursing Care?

Dispute resolution

Challenges to individual decisions

145. 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 CCG with which the individual is a patient for the purposes of NHS continuing healthcare, in line with current DH 'responsible commissioner' guidance (currently *Who Pays? Establishing the Responsible Commissioner*).
146. Whether or not it is considered that the person has a primary health need, the CCG should give clear reasons for its decision. These should set out the basis on which the decision was made and explain the arrangements and timescales for dealing with a review of the eligibility decision in the event that the individual or someone acting on their behalf disagrees with it.
147. 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, if the individual is challenging that decision, this should be addressed through the local resolution procedure (unless the Board decides that requiring the person to do so would cause undue delay)²⁵. Where it has not been possible to resolve the matter through the local procedure the individual may apply to the Board for an independent review of the decision, if they are dissatisfied with:
- a) the procedure followed by the Board or a CCG in reaching its decision as to the person's eligibility for NHS continuing healthcare; or
 - b) the decision regarding eligibility for NHS continuing healthcare

Where the Board, rather than a CCG, has taken an eligibility decision which is subsequently disputed by the individual, the Board must ensure that, in organising a review of that decision, it makes appropriate arrangements as regards the manner in which it organises this review so as to avoid any conflict of interest.

148. If an individual has been screened out from full consideration following use of the Checklist, they may ask the CCG 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 CCG should give this request due consideration,

²⁵ National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012

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.

149. CCGs and the Board should deal promptly with any request to review decisions about eligibility for either NHS continuing healthcare or NHS-funded nursing care.
150. There are two stages involved in dealing with any requests for a review:
 - a) a local review process at CCG level; and
 - b) a request to the Board, which may then refer the matter to an independent review panel.
151. Each CCG should agree a local review process. These review processes should include timescales and should be made publicly available, and a copy should be sent to anybody who requests a review of a decision
152. Once local procedures have been exhausted, the case should be referred to the Board's independent review panel (IRP) (details in Annex E), which will consider the case and make a recommendation to the CCG. If using local processes would cause undue delay, the Board has the discretion to agree that the matter should proceed direct to an IRP, without completion of the local process.
153. The key principles for resolving disputes regarding NHS continuing healthcare eligibility (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;
 - 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.
154. 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 CCG 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.

155. IRPs have a scrutiny and reviewing role. It is therefore not necessary for any party to be legally represented at IRP hearings, although individuals may choose to be represented by family, advocates, advice services or others in a similar role if they wish.
156. The role of the IRP is advisory, but its recommendations should be accepted by the Board (and subsequently by the CCG) in all but exceptional circumstances (see Annex E).
157. If the original decision is upheld and there is still a challenge, the individual has the right to contact the Parliamentary and Health Service Ombudsman to request a review.
158. The individual's rights under the existing NHS and social services complaints procedures remain unaltered by the above.

Practice Guidance Notes – see part 2 of document.

Page 94: There are two different kinds of dispute that may arise in relation to NHS continuing healthcare

Page 95: What issues should be considered at the Checklist stage of the decision-making process to avoid or resolve disputes?

Page 95: What issues should be considered at the DST stage of the decision-making process to avoid or resolve disputes?

Page 96: What factors need to be considered in local disputes processes?

Page 96: What if the dispute crosses CCG/LA borders?

Page 96: What if the individual wishes to challenge the final eligibility decision made by the CCG?

Disputes regarding the responsible body

159. CCGs and LAs in each local area should agree a local disputes resolution process to resolve cases where there is a dispute between them about eligibility for NHS continuing healthcare, about the apportionment of funding in joint funded care/support packages, or about the operation of refunds guidance (see Annex F). 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 CCGs in different geographical areas, the disputes resolution process of the responsible CCG should normally be used in order 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.

160. DH 'responsible commissioner' guidance sets out expectations for when there is a dispute between CCGs as to responsibility. 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 CCG is responsible for funding an individual's healthcare provision. CCGs should agree interim responsibilities for who funds the package until the dispute is resolved. Where the CCGs are unable to resolve their dispute the matter should be referred to the Board.

Practice Guidance Note – see part 2 of document.

Page 97: What can key agencies do to improve partnership working in relation to NHS continuing healthcare?

Governance

161. Both CCGs and the Board have roles in establishing and maintaining governance arrangements for NHS continuing healthcare eligibility processes and commissioning.
162. CCGs 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;
 - g) nominating and making available suitably skilled professionals to be members of Independent Review Panels (in accordance with Standing Rules); and
 - h) informing commissioning arrangements, both on a strategic and an individual basis.
163. CCGs 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 CCGs commission care more efficiently and ensure that the data fed back to the Department and the Board is accurate and consistent.

164. The Board's functions include providing strategic leadership and organisational and workforce development, and ensuring that local systems operate effectively and deliver improved performance. The Board holds CCGs accountable and therefore engages with them to ensure that they discharge their functions. In carrying out this role, the Board should be aware of the range of responsibilities that CCGs hold in relation to NHS continuing healthcare, as detailed in the paragraphs above.
165. The Board will also be responsible for appointing persons to act as chairs of IRPs and establishing a list of IRP panel members drawn from LAs and CCGs, in accordance with Standing Rules (*National Health Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012*).

Practice Guidance Notes – see part 2 of document.

*Page 98: **What is the role of the CCG in relation to NHS continuing healthcare?***

*Page 100: **What is the role of the LA in NHS continuing healthcare?***

*Page 101: **What information is available to give to members of the public about NHS continuing healthcare?***

Commissioning, Care Planning and Provision

Provision

166. 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.
167. Where a person qualifies for NHS continuing healthcare, the package to be provided is that which the CCG assesses is appropriate to meet all of the individual's assessed health and associated social care needs. Although the CCG 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.
168. The LA is, however, not prevented from providing services, subject to the limits outlined in paragraphs 30. Indeed, in some cases, individual arrangements may have to be reached between LAs and CCGs with respect to the provision of services. This may be

particularly relevant if the person is to be cared for in a community setting (see Practice Guidance notes below).

169. CCGs 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.
170. CCGs 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 CCG to an LA (or vice versa).
171. The above approaches apply both to NHS continuing healthcare and to the NHS elements of a joint package.

Equipment

172. 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 CCG. 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 113 - 117, individuals who are entitled to NHS continuing healthcare have an entitlement – on the same basis as other patients – to joint equipment services. CCGs 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. CCGs should make appropriate arrangements to meet these needs. CCGs should ensure that there is clarity about which of the above arrangements is applicable in each individual case.

Access to Other NHS-funded Services

173. 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.
174. The CCG responsible for the individual should be determined in accordance with the principles set out in responsible commissioner guidance.
175. CCGs 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.

Practice Guidance Notes – see part 2 of document.

Page 101: How should care planning be approached for a person entitled to NHS continuing healthcare?

Page 102: Who is responsible for equipment and adaptations if someone is eligible for NHS continuing healthcare and is in their own home?

Page 104: Case Management

Page 105: How should commissioning be approached for a person entitled to NHS continuing healthcare?

Page 106: Can a CCG use an external agency to carry out the commissioning of NHS continuing healthcare services or for negotiation with providers?

Page 107: What limits (if any) can be put on individual choice where, if followed, this would result in the CCG paying for a very expensive care arrangement? Under what circumstances can the CCG decline to provide care in the preferred setting of the individual?

Page 108: Gunter Case

Page 108: What are the responsibilities of CCGs and LAs when a person is Supported in their own home?

Page 109: If a person is in receipt of NHS Continuing Healthcare are they entitled to any local authority funding for social care?

Page 109: If someone receiving NHS Continuing Healthcare also receives some services from the local authority, will they be means tested and charged for these services?

Page 109: If someone has NHS Continuing Healthcare at home, does the PCT have for pay rent/mortgage, food and utility bills?

Page 110: What is the CCG role in relation to carers when someone is in receipt of NHS continuing healthcare?

Page 110: Can a personal health budget be used for people eligible for NHS continuing healthcare?

Page 110: What information and advice is available regarding the development of personalised commissioning and personal health budgets?

Page 111: What practical examples are there of how someone with a primary health need can have their needs met through a 'notional health budget'?

Page 112: What practical options are there for meeting the needs of someone eligible for NHS continuing healthcare by means of a 'real personal budget held by a third party'?

Practice Example – Real Personal Budget Held by Third Party

Page 113: Can the LA be an intermediary for a real personal health budget where the individual has been assessed as having a primary health need? If so, how?

Page 113: Can a local authority act as a 3rd party to administer direct payments to someone who has been deemed eligible for NHS Continuing Healthcare?

Page 114: Can an individual pay for additional services themselves in addition to their NHS continuing healthcare package?

Page 116: Example

Page 117: Example

Page 117: Can an individual 'top-up' their care package to pay for higher-cost services or accommodation?

PART 2 PRACTICE GUIDANCE

Practice Guidance Notes (PG)

PG 1 Is there an authoritative definition of ‘beyond the responsibility of the local authority’?

- 1.1 Local authorities have a duty to carry out an assessment of needs where someone appears to be in need of community care services, and a duty to provide services or support to meet assessed eligible needs. However local authorities cannot lawfully commission services that are clearly the responsibility of the NHS (e.g. care provided by registered nurses and services that the NHS has to provide because the individual is eligible for NHS continuing healthcare).
- 1.2 Whilst there is no legal lower limit to what the NHS can provide, there is a legal upper limit to nursing and healthcare that can be provided by local authorities. This is a complex area of law and there is no simple authoritative definition of what is beyond the responsibility of the local authority. The powers and duties of local authorities are a matter of Statute and case law, including the Coughlan Judgment.
- 1.3 However, local authorities can and do commission care in care homes (with or without nursing) where needs to be met include elements of ‘general nursing’ provided by healthcare assistants or care assistants. A local authority can fund this ‘nursing care’ provided it is both incidental and ancillary to the individual’s accommodation and of a nature that a local authority can be expected to provide.

PG 2 What is the difference between a healthcare need and a social care need?

- 2.1 Whilst there is not a legal definition of a healthcare need (in the context of NHS continuing healthcare), in general terms it can be said that such a need is one related to the treatment, control or prevention of a disease, illness, injury or disability, and the care or aftercare of a person with these needs (whether or not the tasks involved have to be carried out by a health professional).
- 2.2 In general terms (not a legal definition) it can be said that a social care need is one that is focused on providing assistance with activities of daily living, maintaining independence, social interaction, enabling the individual to play a fuller part in society, protecting them in vulnerable situations, helping them to manage complex relationships and (in some circumstances) accessing a care home or other supported accommodation.
- 2.3 Social care needs are directly related to the type of welfare services that LAs have a duty or power to provide. These include, but are not limited to: social work services; advice; support; practical assistance in the home; assistance with equipment and home adaptations; visiting and sitting services; provision of meals; facilities for occupational, social, cultural and recreational activities outside the home; assistance to take advantage of educational facilities; and assistance in finding accommodation (e.g. a

care home), etc. CCGs should be mindful that where a person is eligible for NHS continuing healthcare the NHS is responsible for meeting their assessed health and social care needs.

PG 3 What is a primary health need?

- 3.1 'Primary health need' is a concept developed by the Secretary of State to assist in deciding when the NHS is responsible for meeting an individual's assessed health and social care needs as part of his overall duties under the NHS Act 2006 to provide 'services or facilities for the prevention of illness, the care of persons suffering from illness and the after-care of persons who have suffered from illness' [NHS Act 2006, section 3(1) (e)].
- 3.2 This Framework (paragraph 33) states that '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.'
- 3.3 The term 'primary health need' does not appear, nor is defined, in primary legislation, although it is referred to in the Standing Rules²⁶ where it sets out that a person should be considered to have a primary health need when the nursing or other health services they require, when considered in their totality, are:
- '(a) where that person is, or is to be, accommodated in a care home, more than incidental or ancillary to the provision of accommodation which a social services authority is, or would be but for a person's means, under a duty to provide; or
 - (b) of a nature beyond which a social services authority whose primary responsibility is to provide social services could be expected to provide '
- 3.4 The LA can only meet nursing/healthcare needs when, taken as a whole, the nursing or other health services required by the individual are below this level. If the individual's nursing/healthcare needs, when taken in their totality, are beyond the lawful power of the LA to meet, then they have a 'primary health need'.
- 3.5 Whilst there is not a legal definition, in simple terms an individual has a primary health need if, having taken account of all their needs (following completion of the DST), it can be said that the main aspects or majority part of the care they require is focused on addressing and/or preventing health needs.
- 3.6 Primary health need is not about the reason why someone requires care or support, nor is it based on their diagnosis; it is about their overall actual day-to-day care needs taken in their totality. Indeed it could be argued that most adults who require a package of health and social care support do so for a health-related reason (e.g. because they have had an accident or have an illness or disability). It is the level and type of needs themselves that have to be considered when determining eligibility for NHS continuing healthcare.

²⁶ The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012

- 3.7 Each individual case has to be considered on its own merits in accordance with the principles outlined in this Framework, which cautions against drawing generalisations about eligibility for NHS continuing healthcare from general information about cases reported from court decisions, or by the Parliamentary and Health Service Ombudsman.
- 3.8 Four characteristics of need, namely 'nature', 'intensity', 'complexity' and 'unpredictability' 'may help determine whether the 'quality' or 'quantity' of care required is beyond the limit of an LA's responsibilities, as outlined in the Coughlan case (a summary of the case can be found at Annex B). It is important to remember that 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.
- 3.9 It may be helpful for MDTs to think about these characteristics in terms of the sorts of questions that each generates. By the MDT answering these questions they can develop a good understanding of the characteristic in question. The following questions are not an exhaustive list and are not intended to be applied prescriptively.

'Nature' is about the characteristics of both the individual's needs and the interventions required to meet those needs.

Questions that may help to consider this include:

- How does the individual or the practitioner describe the needs (rather than the medical condition leading to them)? What adjectives do they use?
- What is the impact of the need on overall health and well-being?
- What types of interventions are required to meet the need?
- Is there particular knowledge/skill/training required to anticipate and address the need? Could anyone do it without specific training?
- Is the individual's condition deteriorating/improving?
- What would happen if these needs were not met in a timely way?

'Intensity' is about the quantity, severity and continuity of needs.

Questions that may help to consider this include:

- How severe is this need?
- How often is each intervention required?
- For how long is each intervention required?
- How many carers/care workers are required at any one time to meet the needs?
- Does the care relate to needs over several domains?

'Complexity' is about the level of skill/knowledge required to address an individual need or the range of needs and the interface between two or more needs.

Questions that may help to consider this include:

- How difficult is it to manage the need(s)?

- How problematic is it to alleviate the needs and symptoms?
- Are the needs interrelated?
- Do they impact on each other to make the needs even more difficult to address?
- How much knowledge is required to address the need(s)?
- How much skill is required to address the need(s)?
- How does the individual's response to their condition make it more difficult to provide appropriate support?

'Unpredictability' is about the degree to which needs fluctuate and thereby create challenges in managing them.

Questions that may help to consider this include:

- Is the individual or those who support him/her able to anticipate when the need(s) might arise?
- Does the level of need often change? Does the level of support often have to change at short notice?
- Is the condition unstable?
- What happens if the need isn't addressed when it arises? How significant are the consequences?
- To what extent is professional knowledge/skill required to respond spontaneously and appropriately?
- What level of monitoring/review is required?

PG 4 What are the key elements of a 'person-centred' approach in NHS continuing healthcare?

4.1 The whole process of determining eligibility and planning and delivering services for NHS continuing healthcare should be 'person-centred'. This is vital since individuals going through this process will be at a very vulnerable point in their lives. There may well be difficult and significant choices to be made, so empowering individuals at this time is essential. This approach is also at the heart of wider policy on the personalisation of health and social care services.

4.2 Despite professional intentions to treat individuals with dignity and respect, the perception of individuals can be that this is not always the case. It is important for practitioners to put themselves in the position of the individual by asking questions like:

'How would I feel if this was happening to me?'

'Have I really tried to understand what this person wants, what is important to them now and for the future?'

4.3 There are many elements to a person-centred approach but as a minimum it is necessary to:

- a) ensure that the individual and/or their representative concerned is fully and directly involved in the assessment and the decision-making process;

- b) take full account of the individual's own views and wishes, ensuring that their perspective is clearly the starting point of every part of the assessment process;
- c) address communication and language needs;
- d) obtain consent to assessment and sharing of records (where the individual has mental capacity to give this);
- e) deal openly with issues of risk; and
- f) keep the individual (and/or their representative) fully informed.

a), b) and c) are explained further here, d), e) and f) are explained further in later sections of this guidance

a) Ensuring that the individual concerned and/or their representative is fully and directly involved in the assessment and the decision-making process

Individuals being assessed for NHS continuing healthcare are frequently facing significant changes in their life. It is essential that a person-centred approach is taken throughout the assessment process. A positive experience of the assessment process that promotes genuine choice and control can empower the person, resulting in a much better outcome.

The DST specifically asks whether the individual was involved in the completion of the DST, whether they were offered the opportunity to have a representative and whether the representative attended the DST completion. It also asks for details of the individual's view of their own care/support needs, whether the MDT assessment accurately reflects these and whether they contributed to the assessment. It also asks for the individual's views on the completion of the DST, including their view on the domain levels selected. The provision of advocacy, where appropriate, is an important means of achieving meaningful participation (see PG9 below).

b) Taking full account of the individual's own views and wishes, ensuring that their perspective is clearly the starting point of every part of the assessment process

The individual's own views of their needs and their preference as to how they should be met should be documented at each stage. They should be given as much choice as possible, particularly in the care planning process. Where mental capacity issues impact on an individual's ability to express their views the approaches set out in this guidance should be used, including using family members and others who know the individual well to find out as much as possible on what the individual would want if they were able to express a view.

Where issues arise from needs and risks that may affect the care/support options available, these should be fully discussed with the individual. Care should be taken to avoid indicating any firm conclusions about care/support arrangements until needs have been fully assessed and it is clear what the funding arrangements may be.

c) Addressing communication and language needs

It is important to establish at the outset whether the individual has any particular communication needs and if so how these can be addressed. If English is not their first language an interpreter may be required, or if they have a learning disability the use of photographs, pictures or symbols may be helpful to support communication. Hearing difficulties are often exacerbated where there is background noise (so a quiet room might be needed), and many older people in particular struggle to use any hearing aid they may have. If the individual uses British Sign Language (BSL) it will be necessary to arrange for a BSL interpreter, which may have to be booked well ahead. CCGs should consider the most likely communication needs to arise in the course of assessing for NHS continuing healthcare and make ongoing arrangements for appropriate support to be readily accessible. This could be, for example, by having arrangements with identified formal interpreters to be available at short notice.

Preferred methods of communication should be checked with the person or their relatives, friends or representatives in advance. Where a person has specific communication needs such that it takes them longer than most people to express their views, this should be planned into the time allocated to carry out their assessment.

The overall approach to carrying out the assessment is of equal importance in terms of accessibility to the technical arrangements that are put in place. Many people will find it easier to explain their view of their needs and preferred outcomes if the assessment is carried out as a conversation, dealing with key issues as the discussion naturally progresses, rather than working through an assessment document in a linear fashion. It is important that the person's own view of their needs is treated equally alongside professional views.

PG 5 What specific guidance is there in relation to dealing with confidentiality?

General Principles

- 5.1 Where the person has mental capacity their informed consent is required before completion of the Checklist and for every stage of the process. It is good practice to seek consent for the whole process at the same time as obtaining consent for the Checklist (i.e. for the individual to also explicitly agree to the MDT sharing assessment information and completing the DST), although it should be made clear to individuals that they can withdraw their consent at any time and it would be good practice to ensure that the person is still consenting at each stage.
- 5.2 'Confidentiality: NHS Code of Practice'²⁷ is applicable to decisions on NHS continuing healthcare eligibility. The Code states:

'It is extremely important that patients are made aware of information disclosures that

²⁷

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4069254.pdf

must take place in order to provide them with high quality care' ... 'whilst patients may understand that information needs to be shared between members of care teams and between different organisations involved in healthcare provision, this may not be the case and the efforts made to inform them should reflect the breadth of the required disclosure. This is particularly important where disclosure extends to non-NHS bodies'

and:

'... Patients generally have the right to object to the use and disclosure of confidential information that identifies them, and need to be made aware of this right. Sometimes, if patients choose to prohibit information being disclosed to other health professionals involved in providing care, it might mean that the care that can be provided is limited and, in extremely rare circumstances, that it is not possible to offer certain treatment options.'

Patients must be informed if their decisions about disclosure have implications for the provision of care or treatment. Clinicians cannot usually treat patients safely, nor provide continuity of care, without having relevant information about a patient's condition and medical history.'

'Where patients have been informed of:

*a. the use and disclosure of their information associated with their healthcare; and
b. the choices that they have and the implications of choosing to limit how information may be used or shared then explicit consent is not usually required for information disclosures needed to provide that healthcare. Even so, opportunities to check that patients understand what may happen and are content should be taken...'*

- 5.3 When explicit consent is sought from patients, the Code advises that there should be evidence that consent has been given, either by noting this within a patient's health record or by including a consent form signed by the patient.
- 5.4 When requesting consent to consider an individual's eligibility for NHS continuing healthcare, this should also include consent to obtain relevant health and social care records necessary to inform determination of eligibility and also consent for these to be shared appropriately with those involved in the eligibility process. Individuals should be made aware of the range of records which may be disclosed and the range of health and social care professionals who may need to read them. The records that may be required to reach an informed conclusion on eligibility could include those from GPs, hospitals, community health services, LA social care, care homes and domiciliary care/support services.
- 5.5 Whilst it may not be possible at the outset in every case to indicate the exact records that may be required, individuals should be aware of the range of records that may be requested and explicitly give their consent to this range. A key question to consider is whether a professional receiving a request for access to the individual's records, exercising reasonable care, would be satisfied that the consent supplied by the individual is sufficiently clear and specific for them to be able to release the records. Whilst it is preferable for consent to be recorded in writing, there may be circumstances where an individual is not physically able to provide written evidence of consent but is able to express their consent through verbal or other means. In such cases, the fact that

consent has been given should be recorded in the patient's notes and evidence of it made available to other professionals when records are required.

- 5.6 Individuals should always be given the option to withhold consent to accessing specific records where they wish, or for personal information being shared with particular people or agencies. The implications of withholding consent on the ability of the MDT or CCG to reach an informed decision in eligibility should be explained to the individual. However, they should never be put under pressure to give consent. Practitioners should respect confidentiality and ensure that information is not shared with third parties where consent has not been given.

Where the individual lacks capacity

- 5.7 Where the individual lacks mental capacity to consent to sharing personal information a 'best interest' decision must be made regarding the need to share information with relevant 3rd parties. Under normal circumstances information sharing between professionals regarding a person who lacks capacity can routinely occur as a best interest decision, subject to any local information sharing protocol that may be in place.
- 5.8 Anyone who holds information regarding someone who lacks mental capacity has a responsibility to act in that person's best interest and this can extend to sharing that information with relevant 3rd parties in appropriate circumstances.
- 5.9 There are some circumstances where information **must** be shared with a 3rd party e.g. where they have a registered Lasting Power of Attorney (Welfare) or are a court appointed Deputy (Welfare).
- 5.10 There are also circumstances where it would be acceptable for a 3rd party who is assuming responsibility for acting in a person's best interest (but may not have the formal authority of being an LPA (Welfare) or Court Appointed Deputy (Welfare)) to legitimately request information. In deciding whether to share personal/clinical information regarding someone who lacks mental capacity with a family member, or anyone purporting to be representing the individual, the information holder must act within the following principles:
- any decision to share information must be in the individual's best interest;
 - the information which is shared should only be that which it is necessary in order for the 3rd party to act in the individual's best interests.

Subject to the above principles, information should not be unreasonably withheld.

- 5.11 There are a number of situations where a 3rd party may legitimately be given information so long as the above principles are followed. Some common examples include:
- someone making care arrangements who requires information about the individual's needs in order to arrange appropriate support;
 - someone with an LPA (finance), Deputyship (finance) or a registered Enduring Power of Attorney (EPA) seeking to challenge an eligibility decision, or any other person acting in the person's best interests to challenge an eligibility decision

PG 6 What happens if an individual with mental capacity refuses to give consent to being considered for NHS continuing healthcare eligibility?

- 6.1 Apart from the guidance given in this Framework, The Reference guide to consent for examination or treatment (second edition 2009)²⁸, although focused on examination and treatment issues contains principles that should also be taken into account when considering a situation where the individual refuses consent to being considered for NHS continuing healthcare eligibility.
- 6.2 If an individual refuses to consent to the completion of a Checklist or NHS continuing healthcare assessment it should be clearly explained that this could potentially affect the ability of the NHS and the LA to provide appropriate services. The reasons for their refusal should be explored. It should be explained that, if they are found to be eligible for NHS continuing healthcare, the NHS has responsibility for funding the support necessary to meet their assessed health and social care needs. It is important to clearly document the efforts made to resolve the situation, including information and explanations given to the individual and his/her representative (where applicable).
- 6.3 Every effort should be made to encourage the individual to be considered for eligibility for NHS continuing healthcare, dealing with any concerns that they may have about this. For example, their reason for refusing consent could be a concern about losing an existing or potential direct payment arrangement, or that the level of funding available to support them might be reduced. The individual should be advised on what the CCG can do to personalise care/support and give them as much control as possible. Fuller details of approaches on this are in paragraphs 166 – 171 of the National Framework.
- 6.4 If an LA decides that the refusal to consent to an assessment for NHS continuing healthcare means that LA services can no longer be provided, they should give reasonable notice and clear reasons to the person concerned and give them the opportunity to request a review of the decision or to take it through the complaints process.
- 6.5.1 Although refusal of consent only occurs in a minority of cases, CCGs and LAs should consider developing jointly agreed protocols on the processes to be followed. These should provide clarity regarding approaches such as the use of existing assessments and other information to determine each organisation's responsibilities and the most appropriate way forward. The aim should be for practitioners to be clear on their responsibilities and how to escalate the case if necessary, and that the individual affected can make an informed decision on future support options as quickly as possible.

PG 7 What if there are concerns that the individual may lack capacity to consent to the completion of a Checklist/DST?

- 7.1 An individual is presumed to have capacity unless it is established that they lack

²⁸ http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_103653.pdf

capacity to make the particular decision in question at the time that it needs to be made. Where there is concern that the person may lack capacity in respect of the particular decision, consideration first needs to be given to whether there is any form of help (for example with communication) that would enable them to make the decision. A capacity test should be made and recorded in accordance with the Mental Capacity Act. Where it has been established that someone lacks mental capacity on a significant issue it is essential that that a third party takes responsibility for making a 'best interests' decision.

- 7.2 Carrying out an assessment for consideration of NHS continuing healthcare eligibility is a 'welfare decision' in the context of the Mental Capacity Act and therefore the decision as to whether or not an assessment is in the person's best interests is the responsibility of the person carrying out the assessment or related process. Where a Checklist or Fast Track Pathway Tool is being completed, responsibility will usually lie with the person completing the Tool. Where a CCG, in accordance with the expectations of the Framework, has appointed a coordinator for the NHS continuing healthcare eligibility process, this person will usually have the responsibility. CCGs and LAs should ensure that all staff involved in NHS continuing healthcare assessments are appropriately trained in Mental Capacity Act principles and responsibilities. Where the assessor is not familiar with Mental Capacity Act principles and the person appears to lack capacity they should consult their employing organisation and ensure that appropriate actions are identified.
- 7.3 An exception to the above is where a third party has been appointed as a 'personal welfare attorney', i.e. has been given personal welfare lasting power of attorney (LPA) by the person when they had mental capacity or has been appointed as a 'personal welfare deputy' by the Court of Protection after the person lost capacity. If someone states that they have such authority the assessor should request a certified copy of the original Deputyship Order or registered LPA and check the wording of the order to confirm that the person does have the relevant authority stated. Where a person has been appointed as attorney or deputy in relation to the person's property and financial affairs only, they would not have authority to make decisions about health and welfare. If they do have the appropriate authority then the assessment cannot continue if the personal welfare attorney or deputy refuses consent. Under these circumstances if the assessor believes that the deputy/attorney's decision is contrary to the best interests of the person, or would seriously compromise them, consideration should be given to raising this concern through the local Safeguarding Adults procedure. In appropriate circumstances the Court of Protection can overrule the decision or withdraw the welfare decision-making authority from the person. Where the third party does not provide a copy of the order or LPA to be checked then decision-making responsibility remains with the assessor (although, dependent upon the urgency of the case, the third party should be given reasonable opportunity to provide the order or LPA if they do not have it with them when requested).
- 7.4 In accordance with the Mental Capacity Act, where a best interests decision needs to be made, the decision-maker should consult with any relevant third party who has a genuine interest in the person's welfare. This will normally include family and friends but can include care workers and paid professionals. In making this decision it is essential that the individual is directly involved in the process, taking into account their views and wishes, including any advance statements (verbal or written).

- 7.5 The decision-maker should take account of the views of those consulted in the best interests process in reaching their final decision. However, those consulted, including family members, do not have the authority to consent to or refuse consent to the actions proposed as a result of the best interests process. The responsibility for the decision rests with the decision-maker, not with those consulted. Where there is a difference of opinion between the decision-maker and those consulted, every effort should be made to resolve this informally. However, this process should not unduly delay timely decisions being made in the person's best interest.
- 7.6 There may be circumstances when a person presents with fluctuating capacity or a temporary loss of decision-making capacity. In these circumstances a decision needs to be made as to whether it would be in the person's best interests to delay seeking consent until capacity is regained. If this is the case, the best interests decisions to be made may also include whether to provide an interim care/support package.

PG 8 When is it appropriate to involve an Independent Mental Capacity Advocate (IMCA)?

- 8.1 An IMCA does not routinely need to be appointed in the context of an NHS continuing healthcare assessment. However, NHS bodies and LAs have a duty under the Mental Capacity Act 2005 to instruct and consult an IMCA if an individual lacks capacity in relation to an accommodation move, serious medical treatment or a hospital admission for longer than 28 days and has no family or friends that are available (or appropriate) for consultation on their behalf.
- 8.2 Where an IMCA has been appointed a permanent decision should not be made on the issue (for which they have been appointed) until the IMCA report has been submitted and considered by the decision-maker.

PG 9 Whose responsibility is it to provide advocacy for individuals going through the eligibility decision-making process?

- 9.1 Any individual is entitled to nominate an advocate to represent their views or speak on their behalf and this could be a family member, friend, a local advocacy service or someone independent who has an advocacy role. It is not appropriate for either an LA or NHS member of staff to act as a formal advocate in this sense as there could be a conflict of interest, although staff should always seek to explain the individual's views alongside their own. LAs and CCGs will have varying arrangements to fund independent advocacy services in their locality, some being jointly funded whereas others are funded by a single agency or rely on voluntary contributions.
- 9.2 In considering whether any strategic action is needed to ensure adequate advocacy services are available, the CCG might develop protocols with local advocacy services about how they will support individuals around NHS continuing healthcare, making sure that the services have sufficient capacity to meet likely demand. Individuals should also be advised of local Independent Complaints Advocacy Service (ICAS) arrangements.
- 9.3 For advocacy in relation to independent review panels (IRPs), CCGs 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. CCGs could link such protocols with the strategic development of advocacy services discussed above.

PG 10 Do individuals need to have legal representation during the NHS continuing healthcare eligibility process?

- 10.1 No, although individuals are free to choose whether they wish to have an advocate present, and to choose who this advocate is. This Framework (supported by Standing Rules Regulations and directions to LAs) sets out a national system for determining eligibility for NHS continuing healthcare. The eligibility process is focused around assessing an individual's needs in the context of the Framework rather than being a legal or adversarial process.
- 10.2 If the individual chooses to have a legally qualified person to act as their advocate, that person would be acting with the same status as any other advocate nominated by the individual concerned. The MDT process is fundamentally about identifying the individual's needs and how these relate to the Framework. Health and social care practitioners should be confident of their knowledge and skill in dealing with most queries that arise about the MDT process and the appropriate completion of the DST. Where wider issues that are not connected with the question of eligibility are raised by advocates (such as legal questions) they should, if appropriate, be asked to raise these separately with the CCG outside the MDT meeting.

PG 11 How should the well-managed need principle be applied?

- 11.1 This Framework provides that the decision-making rationale should not marginalise a need just because it is successfully managed: well-managed needs are still needs. The DST user notes provide additional guidance on the application of this principle at paragraphs 27 – 29. An example of this might occur in the context of the behaviour domain where an individual's support plan includes support/interventions to manage challenging behaviour, which is successful in that there are no recorded incidents which indicate a risk to themselves, others or property. In this situation, the individual may have needs that are well-managed and if so, these should be recorded and taken into account in the eligibility decision. In applying the principle of well-managed need, consideration should be given to the fact that specialist care-providers may not routinely produce detailed recording of the extent to which a need is managed. It may be necessary to ask the provider to complete a detailed 24/48 hour diary to demonstrate the nature and frequency of the needs and interventions, and their effectiveness.
- 11.2 Care should be taken when applying this principle. Sometimes needs may appear to be exacerbated because the individual is currently in an inappropriate environment rather than because they require a particular type or level of support – if they move to a different environment and their needs reduce this does not necessarily mean that the need is now 'well managed', the need may actually be reduced or no longer exist. For example, in an acute hospital setting, an individual might feel disoriented or have difficulty sleeping and consequently exhibit more challenging behaviour, but as soon as they are in a care home environment, or their own home, their behaviour may improve

without requiring any particular support around these issues.

- 11.3 The fact that an individual has a well-managed need does not, of itself, mean that they are either eligible or not eligible for NHS continuing healthcare. However, well-managed needs should be considered as part of the eligibility decision-making process. For more information see DST user notes paragraph 27.

PG 12 Dealing openly with issues of risk

- 12.1 Assessment of risk is central to providing a holistic multidisciplinary assessment of need. A good risk assessment will include listening and observation, talking to the individual and their carers to identify what risks they see and their proposed response to them in the context of their personal and family circumstances, talking to other agencies and providers of services and then listing the key risk factors, for example isolation, self neglect, self harm or aggression. In considering 'risk' it is important to establish what particular adverse occurrence might happen and to evaluate both the likelihood and the potential impact of this occurrence.
- 12.2 So long as an individual has mental capacity they are entitled to choose to take risks, even if professionals or other parties consider the decision to be unwise. It is important to work with the person to explain any risks involved and not to make generalised assumptions about these. 'Independence, choice and risk: a guide to best practice in supported decision-making²⁹' sets out wider best practice on this issue. The governing principle it states for dealing with independence, choice and risk for all activities surrounding a person's choices about their daily living is: 'People have the right to live their lives to the full as long as that doesn't stop others from doing the same.'
- 12.3 To put this principle into practice, those supporting individuals have to:
- help people have choice and control over their lives
 - recognise that making a choice can involve some risk
 - respect people's rights and those of their family carers
 - help people understand their responsibilities and the implications of their choices, including any risks
 - acknowledge that there will always be some risk, and that trying to remove it altogether can outweigh the quality of life benefits for the person
 - continue existing arrangements for safeguarding people.
- 12.4 The guidance also includes best practice approaches to decision-making on risk issues, including a supported decision tool.
- 12.5 Where someone lacks the mental capacity to make a decision about a course of action, including one involving any level of risk, they will not be able to give consent. In these circumstances, any decision or action should be made on the basis of what is in the person's best interests, following the requirements in the Mental Capacity Act 2005. In some circumstances, the Court of Protection may need to be involved in certain decisions. It should also be borne in mind that just because a person wishes to make

²⁹ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074773

an unwise decision, this does not mean in itself that they lack capacity to make the decision.

Hospital Discharge Policy and Interim Processes

PG 13 How does NHS continuing healthcare fit with hospital discharge procedures?

- 13.1 Arrangements for applying the Framework should form an integral part of local hospital discharge policies, and should be implemented in such a way that delays are minimised. Timely assessments will prevent whole system delays within the acute hospital sector. LAs, CCGs and other NHS bodies providing hospital services should ensure that there is clarity in local discharge protocols and pathways about how NHS continuing healthcare fits into these processes, and what their respective responsibilities are.
- 13.2 CCGs should ensure that discharge policies with providers who are not NHS trusts are clear. Where appropriate, the CCG may wish to make provisions in its contract with the provider.
- 13.3 The 'delayed discharges' procedures (such as the issuing of section 2 and section 5 notices under the Community Care (Delayed Discharges etc.) Act 2003 as amended) are not triggered until the NHS trust or NHS foundation trust are satisfied that the relevant individual is not entitled to NHS continuing healthcare.
- 13.4 Where it appears to an NHS trust or NHS foundation trust that a person planned to be discharged from hospital may have a need for NHS continuing healthcare, a decision on eligibility should be made prior to notices being issued under delayed discharges legislation unless alternative NHS-funded services are provided.
- 13.5 It is preferable for eligibility for NHS continuing healthcare to be considered after discharge from hospital when the person's long-term needs are clearer, and for NHS-funded services to be provided in the interim. This might include therapy and/or rehabilitation, if that could make a difference to the potential further recovery 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. Where a person is discharged from hospital with such interim services in place delayed discharges legislation does not apply.
- 13.6 Social care practitioners should work jointly with NHS staff throughout the NHS continuing healthcare eligibility process, and should be involved as part of the MDT wherever practicable. Therefore, where the LA receives a referral for involvement in the MDT process for NHS continuing healthcare they should respond positively and promptly. The LA should usually be represented on the MDT completing the NHS continuing healthcare eligibility process. This means that, in most cases, the key assessment information needed for LA support is already available if the delayed discharge process is triggered subsequently. Therefore, where a person is found to be ineligible for NHS continuing healthcare and delayed discharge notices are then issued, the LA should be in a position to respond and action their responsibilities within a short timeframe.

- 13.7 CCGs and LAs could consider developing an agreed format for the NHS continuing healthcare multidisciplinary assessment that is also suitable for use as a community care assessment if the person is found ineligible for NHS continuing healthcare and delayed discharge processes are triggered.
- 13.8 In summary, CCGs should have appropriate processes and pathways in place to ensure that, where an individual may have a need for support after hospital discharge, one of the following scenarios will apply:
- a) prior to completing a Checklist in hospital a decision is made to provide interim NHS-funded services to support the individual after discharge (in which case the delayed discharge provisions would not be triggered). In such a case, before the interim NHS-funded services come to an end, consideration of NHS continuing healthcare eligibility should take place through use of the Checklist and, where appropriate, the full MDT process using the DST;
 - b) a Checklist is completed which indicates the person may have a need for NHS continuing healthcare and interim NHS-funded services are put in place to support the individual after discharge until a full MDT NHS continuing healthcare assessment is completed (in which case the delayed discharge provisions would not be triggered); or
 - c) a Checklist is completed which indicates the person may have a need for NHS continuing healthcare and a full MDT NHS continuing healthcare assessment takes place before discharge. If this results in eligibility for NHS continuing healthcare then the delayed discharge procedures do not apply as the NHS continues to have responsibility for the individual's care; or
 - d) a Checklist is completed which indicates the person may have a need for NHS continuing healthcare and a full MDT NHS continuing healthcare assessment takes place before discharge. If this does not result in eligibility for NHS continuing healthcare then the appropriate delayed discharge notices should be issued; or
 - e) a Checklist is completed before discharge which does not indicate the person may have a need for NHS continuing healthcare in which case the appropriate delayed discharges notices should be issued.

If a local area does not use the Checklist either generally or in individual cases then a full MDT NHS continuing healthcare assessment should take place before delayed discharge notices are issued.

PG 14 How does NHS continuing healthcare link with intermediate care?

- 14.1 Intermediate care is aimed at people who would otherwise face unnecessarily prolonged hospital stays or inappropriate admission to acute or longer-term in-patient care or long-term residential care. It should form part of a pathway of support. For example, intermediate care may be appropriately used where a person has received other residential rehabilitation support following a hospital admission and, although having improved, continues to need support for a period prior to returning to their own home. It should also be used where a person is at risk of entering a care home and requires their

needs to be assessed in a non-acute setting with rehabilitation support provided where needed. This is irrespective of current or potential future funding streams, but is clearly important in the context of consideration for NHS continuing healthcare.

- 14.2 CCGs should have regard to the most recent guidance in relation to Intermediate Care.
- 14.3 Individuals should not be transferred directly to long-term residential care from an acute hospital ward unless there are exceptional circumstances. Such circumstances might include:
- a) those who have already completed a period of specialist rehabilitation, such as in a stroke unit
 - b) those who have had previous failed attempts at being supported at home (with or without intermediate care support)
 - c) those for whom the professional judgement is that a period in residential intermediate care followed by another move is likely to be unduly distressing.
- 14.4 The guidance referred to above sets out what intermediate care should look like as well as how to commission it, with an emphasis on partnership working. CCGs should seek to ensure that this pathway is followed prior to any long-term placement apart from exceptional circumstances.

Screening for NHS Continuing Healthcare – the Use of the Checklist Tool

PG 15 What is the NHS continuing healthcare Checklist?

- 15.1 The Checklist is a screening tool used to help practitioners identify individuals who may need a referral for a full consideration of whether their healthcare needs qualify for NHS continuing healthcare funding. It is important to note that the completion of the Checklist does not indicate that an individual is eligible for NHS continuing healthcare and this should be clearly communicated to the individual and/or their representative prior to its completion.

PG 16 Does everyone need to have a Checklist completed?

- 16.1 No, there will be many situations where it is not necessary to complete a Checklist. However, Standing Rules require CCGs to take reasonable steps to ensure that individuals are assessed for NHS continuing healthcare in all cases where it appears to them that there may be a need for such care. Local joint health and social care processes should be in place to identify individuals for whom it may be appropriate to complete a Checklist, including individuals in community settings within the context of the above duty. As a minimum, wherever an individual requires a care home placement or has significant support needs, a Checklist would be expected to be completed (unless the decision is made to go straight to the completion of a DST).

- 16.2 The Standing Rules state that the Checklist is the only screening tool that can be used. CCGs can choose not to use a screening tool, either generally or in individual cases, and instead directly use the DST but alternative screening tools cannot be used. For example, a CCG and LA might agree that everyone who moves from an acute hospital setting into a care home with nursing should automatically have a full DST completed without the need to complete a Checklist.
- 16.3 LAs must notify a CCG and invite them to assist in the completion of a community care assessment³⁰ where a person appears to have health needs, identified as part of the community care assessment process, that could be met by the NHS. Completing a Checklist at the initial assessment or review stage will ensure that people presenting to the LA with health-related needs are properly considered for NHS continuing healthcare eligibility.

PG 17 Who can complete a Checklist?

- 17.1 The aim is that a variety of health and social care practitioners can complete the Checklist in a variety of settings. These could include NHS registered nurses, GPs, other clinicians or LA staff such as social workers, care managers or social care assistants, completing them in an acute hospital, an individual's own home or in a community care setting. It is for each local CCG and LA to identify and agree who can complete the tool but it is expected that it should, as far as possible, include all staff involved in assessing or reviewing individuals' needs as part of their day-to-day work. Such staff should be trained in the Checklist's use and have completion of it as an identified part of their role.

PG 18 When should a Checklist be completed if the individual is in hospital?

- 18.1 In a hospital setting the Checklist should only be completed once an individual's acute care and treatment has reached the stage where their needs on discharge are clear. Paragraph 65 of this Framework highlights the need for practitioners to consider whether the individual would benefit from other NHS-funded care in order to maximise their abilities and provide a clearer view of their likely longer-term needs before consideration of NHS continuing healthcare eligibility. This should be considered before completion of the Checklist as well as before completion of the DST.
- 18.2 In certain cases it can be appropriate for both the Checklist and the DST to be completed within the hospital setting but this should only be where it is possible to accurately identify a person's longer-term support needs at that time and there is sufficient time to identify an appropriate placement/ package of care/support that fully takes into account the individual's views and preferences.
- 18.3 CCGs should ensure that NHS continuing healthcare is clearly built into local agreed discharge pathways. This should include identification of the circumstances when NHS continuing healthcare assessments and care planning will be carried out in the hospital setting.

³⁰ See section 47(3) of the National Health Service and Community Care Act 1990 (c.19), as amended by the Health and Social Care Act 2012.

- 18.4 Checklists should not be completed too early in an individual's hospital stay; this could provide an inaccurate portrayal of their needs as the individual could potentially make further recovery. As far as possible the individual should be ready for safe discharge at the point that the Checklist is undertaken and sent to the CCG. It should therefore be completed at the point where wider post-discharge needs are also being assessed (although before issue of delayed discharge notices). If at any point after a Checklist has been sent to the CCG the individual's needs change such that he/she requires further treatment, the completed Checklist will no longer be relevant and a new Checklist should be undertaken once the treatment has been completed. The CCG and the individual should be kept fully informed of the changed position. This process will enable the CCG to redirect their resources to where they are most urgently required.

PG 19 When should the Checklist be completed if the individual is in the community or in a care setting other than hospital?

- 19.1 In a community setting or a care setting other than hospital it may be appropriate to complete a Checklist:
- as part of a community care assessment
 - at a review of a support package or placement
 - when a clinician such as a community nurse, GP or therapist is reviewing a patient's needs
 - where there has been a reported change in an individual's care needs, or
 - in any circumstance that would suggest potential eligibility for NHS continuing healthcare.

PG 20 Who needs to be present when a Checklist is completed?

- 20.1 The individual should be given reasonable notice of the need to undertake the Checklist. What constitutes reasonable notice depends upon the circumstances of the individual case. In an acute hospital setting or where an urgent decision is needed, notice may only be a day or two days. In a community setting, especially where needs are gradually increasing over time, more notice may be appropriate. The amount of notice given should take into account whether the individual wishes to have someone present to act as an advocate for them or represent or support them, and the reasonable notice required by the person providing that support. It is the responsibility of the person completing the Checklist or coordinating the discharge process to make the individual aware that they can have an advocate or other support (such as a family member, friend or carer) present and of the local arrangements for advocacy support.
- 20.2 The individual themselves should normally be present at the completion of the Checklist, together with any representative in accordance with the above.

PG 21 What information needs to be given to the individual when completing a Checklist?

21.1 The individual and/or their representative should be advised in advance of the need to complete the Checklist and the reasons for this. The DH patient information leaflet on NHS continuing healthcare should be given to the individual. Opportunity should be given for an explanation of the NHS continuing healthcare process to the patient and for dealing with any questions about it. It should be made clear that completion of the Checklist does not indicate likelihood that they will be eligible for NHS continuing healthcare. Whatever the outcome of the Checklist, the individual should be provided with confirmation of this decision as soon as reasonably practicable. The written decision should include the contact details and the complaints process of the CCG in case they want to challenge the Checklist decision (including any review processes available through the CCG as an alternative to making a complaint). Paragraph 21 of the user notes for the Checklist states that 'the individual should be given a copy of the completed Checklist. The rationale contained within the completed Checklist should give enough detail for the individual and their representative to be able to understand why the decision was made.' Therefore a copy of the completed Checklist, together with a covering letter giving the appropriate details for challenging the decision will be sufficient to constitute a written decision in many circumstances, provided that the completed Checklist or other documentation includes sufficient detail for the individual to understand the reasons why the decision was made. CCGs should consider making the decision available in alternative formats where this is appropriate to the individual's needs.

PG 22 What should happen once the Checklist has been completed?

22.1 If full consideration for NHS continuing healthcare is required the Checklist should be sent to the CCG where the individual's GP is registered unless alternative arrangements have been made by the CCG. If the individual does not have a GP, the responsible CCG should be identified using the approaches set out in the 'Who Pays' guidance³¹. Checklists should be sent in the fastest, but most appropriate, secure way, which could include e-mail (if secure) or fax. The use of either internal or external postal systems can delay the receipt of the Checklist and should only be used if no other referral mechanism is available. Each CCG should have appropriate secure arrangements for the receipt of Checklists and these should be publicised to all relevant partners. The CCG will then arrange for a case coordinator to be appointed who will ensure that an MDT (including those currently treating or supporting the individual) carries out an assessment and uses this to complete a DST.

22.2 CCGs have the responsibility for ensuring that arrangements are in place so that individuals who are screened out at the Checklist stage are informed of the outcome, are given a copy of the Checklist, are given details of how to seek a review of the outcome by the CCG and are offered the opportunity for their case to be referred to the LA for consideration for social care support. This could be delegated by agreement to other organisations that have staff completing Checklists but CCGs have the ultimate responsibility.

³¹ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_078466

- 22.3 Where a Checklist indicates that a referral for consideration for NHS continuing healthcare is not necessary, it is good practice for the Checklist to still be sent to the relevant CCG for information, as the individual may wish to request the CCG to reconsider the decision and the CCG will need a copy of the Checklist in order to do this.

PG 23 What evidence is required for completion of the Checklist?

- 23.1 The Checklist is intended to be relatively quick and straightforward to complete. In the spirit of this, it is not necessary to submit detailed evidence along with the completed Checklist. However, the Checklist asks practitioners to record references to evidence that they have used to support the statements selected in each domain. This could, for example, be by indicating that specific evidence for a given domain was contained within the inpatient nursing notes on a stated date. This will enable evidence to be readily obtained for the purposes of the MDT if the person requires full consideration for NHS continuing healthcare.
- 23.2 A 'rationale for decision' box is also included in the Checklist that invites practitioners to give an overall explanation of why the individual should be referred for full assessment of NHS continuing healthcare eligibility. Where referral is based on the numbers of As, Bs and Cs scored, a statement to this effect will often be sufficient. However, an individual may be referred for full assessment despite the fact that the completed domains suggest their needs do not meet the levels required, and in this case a fuller explanation will be important.
- 23.3 Whether or not an individual is being referred for full assessment of eligibility, the completed Checklist should give sufficient information for the individual and the CCG to understand why the decision was reached. Providing as much information as possible will also support the CCG coordinator to put arrangements in place quickly when they receive the Checklist.

PG 24 Can registered nurses in care home settings complete a Checklist Tool?

- 24.1 It is intended that a wide range of NHS and LA social care staff in roles that involve the assessing or reviewing of needs should be able to complete the Checklist. In a care home setting where potential eligibility for NHS continuing healthcare is identified, the care home should contact the relevant CCG NHS continuing healthcare team and ask for a Checklist to be completed, unless the CCG has protocols in place setting out other arrangements for completion of Checklists in these circumstances.

PG 25 Can someone self-refer by completing a Checklist themselves?

- 25.1 No. If the individual is known to a health or social care practitioner, they could ask that practitioner to complete a Checklist. Alternatively, they should contact their CCG NHS continuing healthcare team to ask for someone to visit to complete the Checklist, or if they already have a care home or support provider, they could ask them to contact the

CCG on their behalf. Where the need for a Checklist is brought to the attention of the CCG through these routes it should respond in a timely manner, having regard to the nature of the needs identified. In most circumstances it would be appropriate to complete a Checklist within 14 calendar days of such a request.

PG 26 What is the role of the NHS continuing healthcare coordinator?

26.1 Once an individual has been referred for full assessment for NHS continuing healthcare, the CCG has the responsibility for coordinating the whole process until the eligibility decision is made. The CCG should identify an individual or individuals to carry out the coordination role. Whilst this is likely to be a CCG staff member, it could (by agreement) be a staff member from another organisation such as the LA, an NHS Trust or independent sector organisation. This could be part of a wider inter-agency agreement, or could be negotiated in specific cases due to the skills or responsibilities that the practitioner(s) have in relation to a client group or individual.

26.2 The coordination role includes:

a) receiving and acting upon a referral for assessment of eligibility for NHS continuing healthcare, ensuring appropriate consent has been given

b) identifying and securing the involvement of the MDT which will assess the individual's needs and will then use this information to complete the DST. The MDT should comprise health and social care staff presently or recently involved in assessing, reviewing, treating or supporting the individual

c) supporting MDT members to understand the role they will need to undertake in participating in a multidisciplinary assessment and completing the DST

d) helping MDT members to identify whether they will need to undertake an updated or specialist assessment to inform completion of the multidisciplinary assessment

e) supporting the person (and those who may be representing them) to play a full role in the eligibility consideration process, including ensuring that they understand the process, they have access to advocacy or other support where required, and organising the overall process in a manner that maximises their ability to participate

f) ensuring that there is a clear timetable for the decision-making process, having regard to the expectation that decisions should usually be made within 28 days of the Checklist being received

g) ensuring that the assessment and DST processes are completed in accordance with the requirements in the Framework and relevant Responsibilities Directions

h) acting as an impartial resource to the MDT and the individual on any policy or procedure questions that arise

i) ensuring that the MDT's recommendation on eligibility is sent for approval through the relevant local decision-making processes in a timely manner

j) where local arrangements place the responsibility for informing the individual of the eligibility decision within the role of the coordinator, ensuring that this happens in a timely manner and in accordance with the requirements of the Framework.

26.3 Care should be taken by CCGs to ensure an appropriate separation between the coordinator role and those responsible for making a final decision on eligibility for NHS continuing healthcare.

Keeping the individual informed

26.4 Individuals should be kept fully informed throughout the process. The coordinator should ensure that this takes place, including:

- explaining timescales and key milestones
- making the person aware of other individuals likely to be involved
- informing them of any potential delays
- providing the individual with a key contact person and ensuring a clear channel of communication between them and the MDT
- helping the individual to understand the eligibility process as it progresses. In addition to the national public information leaflet it may be helpful to provide a locally produced information leaflet explaining local processes and giving key contact numbers
- keeping family members appropriately informed, including where the individual indicates that s/he wishes this to take place and where family members will be involved in providing support to the individual and so need to be involved in agreeing their role.

Multidisciplinary Assessment, Completion of the DST and Making Recommendations

PG 27 Why isn't the DST an assessment tool?

27.1 The purpose of the DST is to help identify eligibility for NHS continuing healthcare; it is not designed as an assessment tool in its own right. A good quality multidisciplinary assessment may well identify care/support needs requiring a response by the CCG or LA regardless of eligibility for NHS continuing healthcare. The DST should draw on such an assessment but is itself specifically designed to collate and present the information from the assessment in a way that assists consistent decision-making for NHS continuing healthcare eligibility. The DST is a national tool and should not be altered.

PG 28 What are the elements of a good multidisciplinary assessment?

28.1 Assessment in this context is essentially the process of gathering relevant, accurate and up-to-date information about an individual's health and social care needs, and applying professional judgement to decide what this information signifies in relation to those needs. Both information and judgement are required. An assessment that simply gathers information will not provide the rationale for any consequent decision; an

assessment that simply provides a judgement without the necessary information will not provide the evidence for any consequent decision. Assessment documentation should be obtained from any professional involved in the individual's care and should be clear, well recorded, factually accurate, up to date, signed and dated. As a minimum a good quality multidisciplinary assessment of an individual's health and social care needs will be:

- preceded by informed consent or an appropriate 'best interests' decision as discussed in paragraph 50 of the National Framework
- proportionate to the situation, i.e. in sufficient depth to enable well-informed judgements to be made but not collecting extraneous information which is unnecessary to these judgements. If appropriate this may simply entail updating existing assessments
- person-centred, making sure that the individual and their representative(s) are fully involved, that their views and aspirations are reflected and that their abilities as well as their difficulties are considered
- informed by information from those directly caring for the individual (whether paid or unpaid)
- holistic, looking at the range of their needs from different professional and personal viewpoints, and considering how different needs interact
- taking into account differing professional views and reaching a commonly agreed conclusion
- considerate of the impact of the individual's needs on others
- focused on improved outcomes for the individual
- evidence-based – providing objective evidence for any subjective judgements made
- clear about needs requiring support in order to inform the commissioning of an appropriate care package
- clear about the degree and nature of any risks to the individual (or others), the individual's view on these, and how best to manage the risks.

28.2 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 including the Single Assessment Process for older people³², the Care Programme Approach³³ and the Common Assessment Framework³⁴. Person-centred

³² <http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/SocialCare/Chargingandassessment/SingleAssessmentProcess/index.htm>

³³ <http://www.nhs.uk/carersdirect/guide/mental-health/pages/care-programme-approach.aspx>

plans³⁵ (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 DST. Health action plans and health checks can also provide useful evidence.

28.3 Effective assessment processes and documentation are key to making swift decisions on eligibility for NHS continuing healthcare and for commissioning the right care package at the right time and in the right place, so that the individual can move to their preferred place of choice as quickly and safely as possible.

28.4 CCGs and LAs should consider agreeing joint models of assessment documentation and having regular training or awareness events to support them.

PG 29 Potential Sources of Information/Evidence (not an exhaustive list):

- Health needs assessment
- Community care assessment
- Nursing assessment
- Individual's own views of their needs and desired outcomes
- Person-centred plan
- Carer's views
- Physiotherapy assessment
- Behavioural assessment
- Speech and Language Therapy (SALT) assessment
- Occupational Therapy assessment
- Care home/home support records
- Current care plan
- 24-hour/48-hour diary indicating needs and interventions (may need to be 'good day' and 'bad day' if fluctuating needs)
- GP information
- Specialist medical/nursing assessments (e.g. tissue viability nurse, respiratory nurse, dementia nurse, etc.)
- Falls risk assessment
- Standard scales (such as the Waterlow score)
- Psychiatric/community psychiatric nurse assessments

See also

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083650

³⁴

<http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/CommonAssessmentFrameworkforAdults/index.htm>

³⁵ For information see Think Local Act Personal Website

<http://www.thinklocalactpersonal.org.uk/Regions/EastMidlands/Personalisation/PCP/PCPGuidance>

PG 30 What is a multidisciplinary team in the context of NHS continuing healthcare?

30.1 'Multidisciplinary team' (MDT) has many meanings but in the context of NHS continuing healthcare the Standing Rules Regulations define a 'multidisciplinary team' as:

'(i) two professionals who are from different healthcare professions, or

(ii) one professional who is from a healthcare profession and one person who is responsible for assessing individuals for community care services under section 47 of the National Health Service and Community Care Act 1990'.

30.2 Whilst as a minimum requirement an MDT can comprise two professionals from different healthcare professions, the Framework makes it clear that the MDT should usually include both health and social care professionals, who are knowledgeable about the individual's health and social care needs.

30.3 The individual and/or their representative should be fully involved in the process and be given every opportunity to contribute to the MDT discussion. However, once all the information has been gathered (and depending on agreed local protocols) it is acceptable for the MDT to have a discussion without the individual and/or their representative present in order to come to an agreed recommendation. MDTs should be aware that the DST contains a section at the end of the domain tables for the individual and/or the representative to give their views on the completion of the DST that have not already been recorded elsewhere in the document, including whether they agree with the domain levels selected. It also asks for reasons for any disagreement to be recorded. Therefore the MDT meeting should be arranged in a way that enables that individual to give his/her views on the completed domain levels before they leave the meeting.

30.4 If the individual and/or their representative are not present for the part of the meeting where the MDT agrees the recommendation regarding primary health need, the outcome should be communicated to them as soon as possible.

30.5 MDT members could include:

- nurse assessors
- social care practitioners
- physiotherapists
- occupational therapists
- dieticians/nutritionists
- GPs/consultants/other medical practitioners
- community psychiatric nurses
- ward nurses
- care home/support provider staff
- community nurses
- specialist nurses
- community matrons
- discharge nurses.

This list is not exhaustive but is intended as a prompt of who may need to be invited to provide evidence regarding an individual's needs so that as accurate and comprehensive picture as possible can be made.

PG 31 What happens if the coordinator is unable to engage relevant professionals to attend an MDT meeting?

31.1 CCGs should not make decisions on eligibility in the absence of an MDT recommendation, unless exceptional circumstances require an urgent decision to be made.

31.2 Apart from ensuring that all the relevant information is collated, it is crucial to have a genuine and meaningful multidisciplinary discussion about the correct recommendation to be made. This should normally involve a face-to-face MDT meeting (including the individual and/or their representative). If a situation arises where a relevant professional is unable or unwilling to attend an MDT meeting every possible effort should be made to ensure their input to the process in another way, such as participating in the MDT meeting as a teleconference call. Where this is not possible then submission of a written assessment or other documentation of views could be used but this should be the least favoured option. Where professionals use this route, the CCG should explain to them that, whilst their views will be taken into account, the eligibility recommendation will by necessity be made by MDT members physically present or participating by teleconference.

Care should be taken to ensure that alternative approaches for MDT participation still enable the individual being assessed to fully participate in the process.

31.3 If, even after having followed the above processes, there are still difficulties with the participation of, or obtaining assessment information from, a specific professional, CCGs should consider (in liaison with the individual) whether they have sufficient wider assessment information to reach a full picture of the individual's needs, having regard to the minimum MDT membership set out above. CCGs should record the attempts to secure participation.

31.4 In order to ensure effective MDT decision-making, CCGs should:

a) have arrangements in place for coordinators to obtain senior support to secure participation of other practitioners where necessary

b) consider agreeing protocols on MDT participation with organisations that frequently have staff who participate in MDTs.

PG 32 Where should an MDT meeting take place?

32.1 An MDT meeting can take place in any setting but should be as near to the individual's location as possible so that they are enabled to be actively involved in the process. Although the acute hospital setting is not an ideal place for MDTs to make a recommendation about eligibility, it may, in some circumstances where the person is an

in-patient, be the only available opportunity to have everyone involved in the process but, wherever possible, it should still be held in a suitable room for the nature of the meeting. Alternatives to the acute hospital setting should be used for MDT meetings wherever possible. For example community hospitals, hospices, care homes or the individual's own home may provide suitable settings.

PG 33 What process should be used by MDTs to ensure consistency when completing the DST?

33.1 Whilst local conditions and therefore local processes will vary, the following elements are recommended as being core to achieving consistency:

a) The coordinator should gather as much information as possible from professionals involved prior to the MDT meeting taking place, including agreeing where any new/updated specialist assessments are required prior to the meeting.

b) The coordinator (or someone nominated by them) should explain the role of the MDT to the individual in advance of the meeting, together with details of the ways that the individual can participate. Where an individual requests copies of the documentation to be used this should be supplied.

c) Information from the process above and any additional evidence should be discussed within the MDT meeting to ensure common agreement on individual needs. Where copies of assessments are circulated to MDT members at the meeting, copies should also be made available to the individual if they are present.

d) Relevant evidence (and sources) should be recorded in the text boxes preceding each of the domain levels within the DST and this information should be used to identify the level of need within that domain, having regard to the user notes of the DST.

e) Depending upon local arrangements the MDT members may decide to reach the final recommendation on eligibility after the individual and their representative have left the meeting. However, the above gives clear expectations on their involvement in the wider process. If the MDT is to reach its final recommendation privately it is best practice to give the individual/representative an opportunity before they leave the meeting to state their views.

f) Having completed the care domains, the MDT should consider what this information signifies in terms of the nature, complexity, intensity and unpredictability of the individual's needs. It should then agree and record its recommendation, based on these concepts, providing a rationale which explains why the individual does or does not have a primary health need. It is important that MDT members approach the completion of the DST objectively without any preconceptions that specific conditions or diagnoses do or do not indicate eligibility or fit a particular domain level without reference to the actual needs of the individual (see below for more detail on recommendations).

g) The recommendation should then be presented to the CCG, who should accept this, except in exceptional circumstances. These circumstances could for example include insufficient evidence to make a recommendation or incomplete domains.

h) If the CCG, exceptionally, does not accept the MDT recommendation (see PG41 for circumstances when this can happen) it should refer the DST back to the MDT identifying the issues to be addressed. Once this has been completed the DST should be re-presented to the CCG who should accept the recommendation (except in exceptional circumstances).

i) The decision should be communicated in writing as soon as possible in an accessible format and language to the individual or their representative so that it is meaningful to them. They should also be sent a copy of the DST and information on how to ask for a review of the decision if the individual is dissatisfied with the outcome.

This whole process should usually be completed within 28 (calendar) days. This timescale is measured from the date the CCG receives the completed Checklist indicating the need for full consideration of eligibility (or receives a referral for full consideration in some other acceptable format) to the date that the eligibility decision is made. However, wherever practicable, the process should be completed in a shorter time than this.

PG 34 What is proportionate and reasonable in terms of evidence required to support domain levels and the recommendation in a DST?

34.1 Much will depend on the particular circumstances of the case in question. However, the following points should be born in mind:

- The purpose of evidence in this context is to ensure that there is an accurate picture of the individual's needs, not to convince a court of law that those providing the evidence are telling the truth. Any requirement for additional evidence in support of levels of need should be proportionate and reasonable.
- Having sufficient evidence is not about volume but about how pertinent it is – more is not necessarily better. For example, a précis of incident forms or a chart showing the number of times a particular type of incident/intervention occurred may be more helpful than requiring all the original incident forms or daily records.
- Borderline cases may be aided by more detailed evidence in some domains, to ensure that the portrayal of needs is accurate
- The use of a 24/48 hour diary indicating needs and interventions may well provide very useful evidence
- Oral evidence from carers or relevant professionals should not be disregarded where it is pertinent to establishing the levels of need.

PG 35 What happens if MDT members cannot agree on the levels within the domains of the DST?

35.1 The DST (paragraph 22) advises practitioners to move to the higher level of a domain where agreement cannot be reached but there should be clear reasoned evidence to support this. If practitioners find themselves in this situation they should review the evidence provided around that specific area of need and carefully examine the wording of the relevant DST levels to cross-match the information and see if this provides further clarity to move forwards or seek further evidence, although this should not prolong the

process unduly. If this does not resolve the situation, the disagreement about the level should be recorded on the DST along with the reasons for choosing each level and by which practitioner. This information should also be summarised within the recommendation so that the CCG can note this when verifying recommendations.

- 35.2 The practice of moving to the higher level where there is disagreement should not be used by practitioners to artificially steer individuals towards a decision that they have a primary health need where this is not justified. It is important that this is monitored during the CCG audits of recommendations and processes so that individual practitioners found to be using the 'higher level' practice incorrectly can be identified. Discussion may need to take place with these practitioners and possibly further training offered.
- 35.3 If practitioners are unable to reach agreement, the higher level should be accepted and a note outlining the position included within the recommendation on eligibility. As part of CCGs' governance responsibilities, they should monitor occurrences of this issue. Where regular patterns are identified involving individual teams or practitioners this should be discussed with them and where necessary their organisations to address any practice issues.

PG 36 What happens if the individual concerned or their representative disagrees with any domain level when the DST is completed?

- 36.1 Whilst the individual and/or their representative should be fully involved in the process and be given every opportunity to contribute to the MDT discussion, the formal membership of the MDT consists of the practitioners involved. The approach described in PG35 above applies to disagreements between practitioners and not when an individual or their representative disagrees with individual domain levels chosen in the completion of the DST. However, concerns expressed by individuals and representatives should be fully considered by reviewing the evidence provided. If areas of disagreement remain these should be recorded in the relevant parts of the DST.

PG 37 What does the DST recommendation need to cover?

- 37.1 The recommendation should:
- a) provide a summary of the individual's needs in the light of the identified domain levels and the information underlying these. This should include the individual's own view of their needs.
 - b) provide statements about the nature, intensity, complexity and unpredictability of the individual's needs, bearing in mind the explanation of these concepts provided in paragraphs 77 – 89 of the National Framework.
 - c) give an explanation of how the needs in any one domain may interrelate with another to create additional complexity, intensity or unpredictability.
 - d) in the light of the above, give a recommendation as to whether or not the individual

has a primary health need (with reference to paragraphs 77 – 89 of the National Framework). It should be remembered that, whilst the recommendation should make reference to all four concepts of nature, intensity, complexity and unpredictability, any one of these could on their own or in combination with others be sufficient to indicate a primary health need.

- 37.2 Although the core responsibility of MDTs is to make a recommendation on eligibility for NHS continuing healthcare, the recommendation could also indicate any particular factors to be considered when commissioning/securing the placement or care/support package required to meet the individual's needs (whether or not the individual has a primary health need).
- 37.3 Where the outcomes of the individual care domains do not obviously indicate a primary health need (e.g. a priority level in one domain or severe levels in two domains being found), but the MDT is using professional judgement to recommend that the individual does nonetheless have a primary health need, it is important to ensure that the rationale for this is clear in the recommendation.
- 37.4 Where an individual has a deteriorating condition, practitioners need to take this into account in reaching their conclusion on primary health need, considering the approaches set out in paragraph 38 of this Framework and being mindful of how that condition and the associated needs are going to progress before the next planned review. Where an individual has a deteriorating condition but eligibility for NHS continuing healthcare is not presently recommended, consideration should be given to setting an early review date. This should be clearly highlighted in the recommendation to the CCG who should ensure that the review is arranged at the appropriate time.
- 37.5 The recommendation for eligibility for NHS continuing healthcare should not be based upon an individual's specific condition or disease (e.g. stroke, cancer, Alzheimer's disease, dementia, etc.) but on the needs that are identified. Needs that give rise to eligibility can be from any condition or disease. Just because individuals with a particular condition or disease have previously been found to be eligible for NHS continuing healthcare does not mean that every individual with a similar condition or disease will be eligible. Each individual should be assessed in their own right and evidence provided around the range of their needs; the identification of a primary health need should not be prejudged without going through the proper process in each individual case.
- 37.6 All of the above information should be provided even if the recommendation is that the individual does not have a primary health need. The CCG is responsible for care planning and commissioning 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. However, it is beneficial if the MDT makes recommendations on the care package to be provided, based on the assessment and any care plan already developed, whether the CCG, LA or both will have responsibilities.
- 37.7 The written recommendation needs to provide as much detail as possible, but should be clear and concise, to enable the CCG and the individual to understand the rationale behind the recommendation.

- 37.8 As the individual or their nominated representative should receive a copy of the DST it is important that it is legible, and free from jargon and abbreviations.
- 37.9 A copy of the completed assessment, DST and other documents should be forwarded to the CCG.

PG 38 How does the Decision Support Tool (DST) and primary health need eligibility test apply to people with learning disabilities?

- 38.1 The DST should be used for all adults who require assessment for NHS continuing healthcare, irrespective of their client group/diagnosis. The tool focuses on the individual's needs, not on their diagnosis. Directions require that the DST is used to inform the decision as to whether someone has a primary health need, and if they do they must be deemed eligible for NHS continuing healthcare.
- 38.2 In all cases eligibility for NHS continuing healthcare should be informed by good quality multi-disciplinary assessment. Where the individual has a learning disability it will be important to involve professionals with expertise in learning disability in the assessment process as well as those with expertise in NHS continuing healthcare. It will also be important to ensure that the assessment process is person-centred and that family members/carers are fully and appropriately involved.
- 38.3 Standing Rules set out the meaning of 'Primary Health Need' in relation to the limits of local authority responsibility and paragraph 33 of this Framework explains the primary health need test in some detail. It is important to understand that this test is about the balance of needs once all needs have been mapped onto the DST.
- 38.4 This Framework makes it clear (see paragraph 58) that "the reasons given for a decision on eligibility should not be based on....the use or not of NHS employed staff to provide care; the need for/presence of "specialist staff" in care delivery or any other input related (rather than needs-related) rationale."
- 38.5 The question is not whether learning disability is a health need, but rather whether the individual concerned, whatever client group he or she may come from, has a 'primary health need'.
- 38.6 The indicative NHS continuing healthcare eligibility threshold levels of need as set out in the user notes apply equally to all individuals irrespective of their condition or diagnosis.
- 38.7 Previous or current pooled budget, joint funding, Section 75 agreements or legacy funding arrangements and the funding transfer to local authorities in April 2009 do not alter the underlying principles of NHS continuing healthcare entitlement.
- 38.8 The Department of Health made it clear that the funding transfer to local authorities in 2009 was for social care and did not include those eligible for NHS continuing healthcare³⁶. However this Framework points out that some historic local agreements

³⁶ August 2008 DH letter to Chief Executives of PCTs and Councils (Gateway Reference 9906) "Valuing People Now: Transfer of the responsibility for the commissioning of social care for adults with a learning disability from the NHS to Local Government and transfer of the appropriate funding", Page 5, Para 12 (iii):

relating to particular groups of clients with learning disabilities (for example following hospital/campus closures) can mean that these individuals are not required to be considered separately for NHS continuing healthcare.

- 38.9 It is crucial that the detail of these local agreements are examined in order to clarify whether or not the Framework applies. It is important to ensure that all adults are treated equitably under the Framework.
- 38.10 Some people have concerns about the potential loss of personalisation/control for people with learning disabilities (and other client groups) if their care is commissioned/provided/funded by the NHS. However, CCGs have considerable existing legal powers to maximise choice and control, including the provision of 'personal health budgets'. The Government has announced that from April 2014, anyone in receipt of NHS continuing healthcare will have the right to ask for a personal health budget, including a 'direct payment'.
- 38.11 Whatever the outcome of the eligibility decision regarding NHS continuing healthcare, commissioning should be person-centred and needs-led. NHS commissioners for people with learning disabilities should be familiar with and apply the principles of 'Valuing People' and 'Valuing People Now'. For further information on commissioning and care planning please see paragraphs 108 - 111 of this Framework. This is an area where local authorities and CCGs need to work closely in partnership to ensure the best outcome for the individuals concerned, whether or not the care package is to be fully funded by the NHS.
- 38.12 Where an individual is eligible for NHS continuing healthcare, CCGs have responsibility to ensure that effective case management is commissioned. Consideration should be given as to who is best placed to provide this function, and clear responsibilities agreed. Amongst other options it may be appropriate to secure this from the local authority who may have previous knowledge of the individual concerned or have staff with particular skills and experience to undertake this function on behalf of the CCG. Please see PG80 below regarding responsibilities for case management.

Eligibility and Panel Processes

PG 39 If the CCG uses a panel as part of the decision-making process what should its function be and how should it operate?

- 39.1 There is no requirement for CCGs to use a panel as part of their decision-making processes. Close working with LA social care is an inherent part of this Framework, for example in terms of membership of MDTs and in having local joint processes for resolving disputes. It would be consistent with this overall approach for CCGs to have mechanisms for seeking the views of LA colleagues when making final decisions on NHS continuing healthcare eligibility and this could be by the use of a panel. However the formal decision-making responsibility rests with the CCG. Annex G (Local NHS Continuing Healthcare Protocols) contains details of the recommended content of local protocols, including decision-making processes.

39.2 Panels may be used in a selective way to support consistent decision-making. For example this could include panels considering:

- cases which are not recommended as eligible for NHS continuing healthcare (for audit purposes or for consideration of possible joint funding)
- cases where there is a disagreement between the CCG and the LA over the recommendation – this could form part of the formal disputes process
- cases where the individual or his/her representative is appealing against the eligibility decision
- a sample of cases where eligibility has been recommended for auditing and learning purposes to improve practice (paragraph 83 of the Framework).

39.3 If a CCG chooses to use a panel arrangement as part of the decision-making process this should not be allowed to delay decision-making. Where relevant expertise is considered essential to the panel the CCG should ensure that staff with such expertise are made available in a timely manner.

PG 40 What should the role of the CCG decision-making process be?

40.1 The role of the CCG decision-making processes, whether by use of a panel or other processes should include:

- verifying and confirming recommendations on eligibility made by the MDT, having regard to the issues in PG41 below;
- agreeing required actions where issues or concerns arise.

40.2 CCG decision-making processes should not have the function of:

- financial gatekeeping
- completing/altering DSTs
- overturning recommendations (although they can refer cases back to an MDT for further work in certain circumstances – see below).

PG 41 What are the ‘exceptional circumstances’ under which a CCG or panel might not accept an MDT recommendation regarding eligibility for NHS continuing healthcare?

41.1 Eligibility recommendations must be led by the practitioners who have met and assessed the individual. Exceptional circumstances where these recommendations may not be accepted by a CCG include:

- where the DST is not completed fully (including where there is no recommendation)

- where there are significant gaps in evidence to support the recommendation
- where there is a obvious mismatch between evidence provided and the recommendation made
- where the recommendation would result in either authority acting unlawfully.

41.2 In such cases the matter should be sent back to the MDT with a full explanation of the relevant matters to be addressed. Where there is an urgent need for care/support to be provided, the CCG (and LA where relevant) should make appropriate interim arrangements without delay. Ultimately responsibility for the eligibility decision rests with the CCG.

PG 42 How should decisions be communicated to the individual/representative?

42.1 Once the recommendation is confirmed by the CCG, the individual should be informed in writing in an appropriate language or format as soon as possible (although this could be preceded by verbal confirmation where appropriate), including the reasons for the decision and details of who to contact if they wish to seek further clarification or request a review of the decision. In most circumstances a fully completed DST with a covering letter confirming the decision and giving the above details will be sufficient for this purpose. Confirmation of the care package to be provided could be included within the letter or, if not known at that stage, should be supplied as soon as available.

PG 43 If a person dies whilst awaiting a decision on NHS continuing healthcare eligibility, should a decision still be made in respect of eligibility for the period before their death?

43.1 Where an individual received services prior to their death that could have been funded through NHS continuing healthcare then the eligibility decision-making process should be completed. Where no such services were provided it is not necessary to continue with the eligibility decision-making process.

43.2 Where a decision is made that the individual would have been eligible for NHS continuing healthcare funding then payments should be made in accordance with the guidance on refunds in Annex F of this Framework.

PG 44 In a Fast Track case is it the CCG or the ‘appropriate clinician’ who decides that the individual has a primary health need?

44.1 In Fast Track cases, Standing Rules state that it is the ‘appropriate clinician’ who determines that the individual has a primary health need. The CCG must therefore decide that the individual is entitled to NHS continuing healthcare and should respond promptly and positively to ensure that the appropriate funding and care arrangements are in place without delay.

44.2 The Fast Track Pathway Tool is used when the individual has a rapidly deteriorating condition and the condition may be entering a terminal phase. For the purposes of Fast Track eligibility this constitutes a primary health need. No other test is required. The

completion of the Fast Track Tool is sufficient evidence to establish eligibility;

The Fast Track Pathway Tool for NHS Continuing Healthcare

PG 45 Who can complete the Fast Track Pathway Tool?

45.1 The Fast Track Tool can only be completed by an 'appropriate clinician', and the Responsibilities Directions define an 'appropriate clinician' as a person who is:

- (i) responsible for the diagnosis, treatment or care of the person in respect of whom a Fast Track Pathway Tool is being completed,
- (ii) diagnosing, or providing treatment or care to, that person under the 2006 Act, and
- (iii) a registered nurse or is included in the register maintained under section 2 of the Medical Act 1983.

45.2 Thus those completing the Fast Track Pathway Tool could include consultants, registrars, GPs and registered nurses. This includes relevant clinicians working in end of life care services within independent and voluntary sector organisations if their organisation is commissioned by the NHS to provide the service.

45.3 Whoever the practitioner is, they should be knowledgeable about the individual's health needs, diagnosis, treatment or care and be able to provide reasons why the individual meets the conditions required for the fast-tracking decision. Others involved in supporting an individual with end of life needs, including those working within wider independent or voluntary sector organisations should, with the individual's consent, contact the appropriate clinician responsible for that individual's healthcare to request that the Fast Track Pathway Tool be completed. Alternatively they could approach the relevant CCG and make the request.

PG 46 What is the relationship between the Fast Track Pathway Tool and the Checklist/Decision Support Tool?

46.1 Where it is appropriate to use the Fast Track Pathway Tool, this replaces the need for a Checklist and DST to be completed, although a Fast Track Pathway Tool can also be completed after the completion of a Checklist if it becomes apparent at that point that the relevant criteria are met.

PG 47 Do individuals need to consent to a Fast Track Pathway Tool being completed?

47.1 Yes, individuals need to give informed consent to the completion of the Fast Track Pathway Tool and the clinician completing the Tool should sensitively seek this. It may be useful to link the consent to the completion of a DST where there is a possibility of the need for this to be undertaken at a future date.

47.2 Where an individual is unable to provide consent, the appropriate clinician should make a 'best interests' decision on whether to complete the Fast Track Pathway Tool in accordance with the Mental Capacity Act 2005. PG7 above explains more about the

necessary actions. This best interests process should be carried out without delay, having regard to the intention that the tool should enable individuals to be in their preferred place of care as a matter of urgency.

PG 48 Is the use of the Fast Track Pathway Tool dependent on specific timescales in relation to end of life care?

48.1 No, there are no time limits specified and a decision to use the Fast Track Pathway Tool should not be based solely around an individual's life expectancy. The phrase 'rapidly deteriorating' in the Tool should not be interpreted narrowly as only meaning an anticipated specific or short time frame of life remaining. Similarly the phrase 'may be entering a terminal phase' is not intended to be restrictive to only those situations where death is imminent. Also, someone may currently be demonstrating few symptoms yet the nature of the condition is such that it is clear that rapid deterioration is to be expected before the next planned review. It may therefore be appropriate to use the Fast Track Pathway Tool now in anticipation of those needs arising and agreeing the responsibilities and actions to be taken once they arise, or to plan an early review date to reconsider the situation. It is the responsibility of the clinician referring an individual to base their decision on the facts of the individual's case and healthcare needs at the time. However, a Fast Track Pathway Tool should be supported by a prognosis and/or diagnosis if known, to help enable staff managing the individual's future care needs to plan the care/support that is likely to be required. Use of the Fast Track Pathway Tool is based on the criteria set out in the Responsibilities Directions, not on diagnosis.

PG 49 What evidence is required when completing the Fast Track Pathway Tool?

49.1 The intention of the Fast Track Pathway is that it should enable an individual to access NHS continuing healthcare quickly, with a minimum of delay, and with no requirement to complete a DST. Therefore the completed Fast Track Pathway Tool is in itself sufficient evidence to establish eligibility.

49.2 As it will be necessary to put support services in place promptly, other information about the person's needs and their preferred model of support will help the CCG to identify the types of services required. Use of the Fast Track Pathway Tool should be carried out as part of overall local end of life care approaches and should reflect the best practice set out in the national End of Life Care Strategy³⁷. The identification of the individual's preferences as to the services to be delivered and their locations should be identified using recognised models for end of life care, i.e. the Gold Standards Framework³⁸, Preferred Priorities for Care³⁹. In doing this, it is important to advise the person on the range of options available (e.g. home support, hospice, etc.). CCGs should support clinicians to have up-to-date knowledge of local service options as part of their overall approach to end of life care so that individuals can make an informed choice on their preferences. CCGs are responsible for ensuring that a wide range of service options are available. Work with the individual on their end of life care pathway should be taking place regardless of NHS continuing healthcare eligibility and so should facilitate availability of the required information. NHS continuing healthcare staff should work in

³⁷ <http://www.dh.gov.uk/health/2011/07/end-of-life-care-strategy/>

³⁸ <http://www.goldstandardsframework.org.uk/>

³⁹ <http://www.endoflifecareforadults.nhs.uk/tools/core-tools/preferredprioritiesforcare>

partnership with local end of life care leads in each individual case to ensure there is an agreed pathway and care plan agreed with the individual and/or their carer/representative. This should be regularly reviewed and amended to reflect changing needs.

- 49.3 It is helpful if an indication of how the individual presents in the current setting is included with the Fast Track Pathway Tool, along with the likely progression of the individual's condition, including anticipated deterioration and how and when this may occur. However, CCGs should not require this information to be provided as a prerequisite for establishing entitlement to NHS continuing healthcare. The completed Fast Track Pathway Tool is sufficient in itself to establish entitlement.
- 49.4 It is also important for the CCG to know what the individual or their family have been advised about their condition and prognosis and how they have been involved in agreeing the end of life care pathway (which should reflect the approaches in the End of Life Care Strategy).

PG 50 Can a CCG refuse to accept a completed Fast Track Pathway Tool?

- 50.1 No, the Standing Rules make it clear that the CCG must accept and action the Fast Track Pathway Tool immediately where the Tool has been properly completed in accordance with the criteria for the use of the Tool as explained above.
- 50.2 The purpose of the Tool is to ensure that the individual receives the support they need as quickly as possible without there first having to be a full consideration of eligibility by an MDT applying the four key characteristics using the DST. The CCG does not require any additional evidence to support eligibility although, as explained above, additional information to help identify the support package required can be helpful. CCGs should not decline acceptance of a completed Fast Track Pathway Tool when the Tool states that the criteria are met. The individual should not experience a delay in receiving appropriate care just because a CCG questions whether the circumstances of the individual case are appropriate for use of the Fast Track Pathway Tool, i.e. whether an individual's end of life needs are such that the Fast Track Pathway Tool should have been used.
- 50.3 On receipt of the Fast Track documentation, the CCG should arrange for the care package to be commissioned without delay.
- 50.4 However, exceptionally, there may be circumstances where CCGs receive a completed tool which appears to show that the individual's condition is not related to the above criteria at all, for example if a completed Fast Track Pathway Tool states that the person has mental health needs and challenging behaviour but makes no reference to them having a rapidly deteriorating condition which may be entering a terminal phase. In these circumstances the CCG should urgently ask the relevant clinician to clarify the nature of the person's needs and the reason for the use of the Fast Track Pathway Tool. Where it then becomes clear that the use of the Fast Track Pathway Tool was not appropriate, the clinician should be asked to submit a completed Checklist for consideration through the wider eligibility process.

PG 51 What actions can CCGs take if the Fast Track Pathway Tool is being used inappropriately?

- 51.1 If the CCG has any concerns regarding the way in which particular clinicians/ organisations are using the Fast Track Pathway Tool these should be addressed separately and should not delay the provision of appropriate support for the person concerned.
- 51.2 Each individual CCG should monitor and audit the use of the Fast Track Pathway Tool according to locally agreed processes, and take appropriate action if inappropriate use of this Tool is identified. Actions could include targeting training for specific individuals, raising the issue through management actions, or addressing the issue through contracting and performance routes.

PG 52 How quickly could a hospital discharge take place following the completion of the Fast Track Tool?

- 52.1 Standing Rules state that the CCG must, upon receipt of a completed Fast Track Pathway Tool, decide that the individual is eligible for NHS continuing healthcare. Action should be taken urgently to agree and implement the care package. CCGs should have processes in place to enable such care packages to be implemented quickly. Given the nature of the needs, this time period should preferably not exceed 48 hours from receipt of the completed Fast Track Pathway Tool. CCGs who receive significant numbers of Fast Track Pathway Tools could consider having staff dedicated to implementing fast-track care packages as this will avoid a conflict of time priorities with dealing with non-fast-track applications. Having dedicated staff could also facilitate close working with end of life care teams. CCGs should also consider wider arrangements that need to be in place to facilitate implementation of packages within 48 hours, such as protocols for the urgent provision of equipment. The CCG coordinator and the referrer should communicate effectively with each other to ensure well-coordinated discharge/support provision arrangements.

PG 53 What settings can a Fast Track Pathway Tool be used in?

- 53.1 It is expected that the Tool will most often be used in hospital settings. However, it can be used in any setting where an individual satisfies the criteria for the use of the Tool and they require an package of support in their preferred location. This includes where such support is required for individuals who are already in their own home or are in a care home and wish to remain there. It could also be used in other settings, such as hospices.

PG 54 Does the Fast Track tool need to be completed if the individual is already receiving a care package which could still meet their needs?

- 54.1 Yes. If an individual meets the criteria for the use of the Fast Track Tool this should be used to ensure not only that they receive the care that they require but also that this care is funded by the appropriate body and end-of-life care arrangements are reviewed.
- 54.2 This is important because the individual may at present be funding their own care or the LA may be funding (and charging) when the NHS should now be funding the care in full.
- 54.3 The setting where an individual wishes to be supported as they approach the end of their life may be different to their current arrangements (e.g. even though they are currently in a care home setting they may wish to be supported in their family environment). CCGs should seek to respond positively to such preferences, having regard to best practice set out in wider 'end of life care' policy⁴⁰.
- 54.4 The setting is not the important issue but rather that the individual concerned receives the support they need in their preferred place as soon as reasonably practicable, without having to go through the full process for consideration of NHS continuing healthcare eligibility.

PG 55 Should individuals receiving care via the Fast Track Pathway Tool have their eligibility for NHS continuing healthcare reviewed?

- 55.1 The aim of the Fast Track Pathway Tool is to get an appropriately funded care package in place as quickly as possible. Once this has happened, it will be important to review needs and the effectiveness of the care arrangements, in line with national guidance (i.e. as a minimum within 3 months). In doing this, there may be certain situations where the needs indicate that it is appropriate to review eligibility for NHS continuing healthcare funding. CCGs should make any decisions about reviewing eligibility in Fast Track cases with sensitivity. Where it is apparent that the individual is nearing the end of their life and the original eligibility decision was appropriate it is unlikely that a review of eligibility will be necessary. CCGs should monitor care packages to consider when and whether a review is appropriate.
- 55.2 Clinicians completing the Fast Track Pathway Tool should sensitively explain the process to the individual (and/or their representative) and make them aware that their needs may be subject to a review and that the funding stream may change subject to the outcome of the review.
- 55.3 Eligibility for NHS continuing healthcare can only be ended by a review through the use of the full MDT-led DST process. The individual affected should be notified in writing of any proposed change in funding responsibility. They should be given details of their right to request a review of the decision. There should be as much continuity as possible in the care arrangements, for example by carrying on with use of the same care providers wherever possible.

⁴⁰ <http://www.dh.gov.uk/health/category/policy-areas/social-care/end-of-life/>

PG 56 Can the national tools be changed?

- 56.1 No, these are national tools and the content should not be changed, added to or abbreviated in any way. However, CCGs may attach their logo and additional patient identification details if necessary (e.g. adding NHS number, etc.).

PG 57 Why is it important to complete the equality monitoring forms with the tools?

- 57.1 The equality monitoring form is for completion by the individual being assessed, although staff should offer to help them complete it where support is required. The purpose of the equality monitoring form is to help CCGs identify whether individuals from different groups (in terms of disability, ethnicity, etc.) are accessing NHS continuing healthcare on an equitable basis, including whether they are being properly identified for potential eligibility at Checklist stage and are being identified for the Fast Track process where appropriate. The equality form should be forwarded separately from the Tools to the relevant CCG to enable it to monitor whether the Framework is being applied equitably in its area. If the CCG identifies any issues for particular groups or communities it should take steps to address these.

PG 58 What are joint packages of care?

- 58.1 Where an individual's care/support package is supported by both the NHS and the LA this is known as a 'joint package of care'. The Framework advises that if an individual does not qualify for fully funded NHS continuing healthcare the NHS may still have a responsibility to contribute to meeting that individual's healthcare needs. The respective powers and responsibilities of each organisation should be identified by considering the needs of the individual. Where there are overlapping powers and responsibilities, a flexible, partnership-based approach should be adopted based on the most appropriate organisation to meet the specific need.
- 58.2 Although the LA can provide some healthcare services (within legal limitations of LA social care powers) the assessment and DST may have identified some healthcare needs that are not of a nature that the LA could solely meet, or that are beyond the powers of the LA to solely meet, and therefore these may be the responsibility of the NHS to provide. Practitioners should draw on their knowledge and skills regarding the assessed needs and their organisation's powers to meet them, and work together to agree respective responsibilities for care provision in a joint package of care.
- 58.3 In a joint package of care the CCG and the LA can each contribute to the package by:
- a) delivering direct services to the individual
 - b) commissioning care/services to support the care package, or
 - c) transferring funding between their respective organisations (where the needs are ones that the NHS and the LA both have the power to meet).

58.4 Although the funding for a joint package comes from more than one source it is quite possible that one provider, or the same worker(s), could provide all the support. Joint care packages can be provided in any setting. Examples can include:

- someone in their own home with a package of support who does not have a primary health need but has a package of support comprising both health and social care elements
- someone in a care home with nursing who has nursing or other health needs that, whilst not constituting a primary health need, are clearly above the level of needs intended to be covered by NHS-funded nursing care
- someone in a care home (without nursing) who, although not eligible for NHS continuing healthcare, has some specific health needs beyond the power of the LA to meet, requiring skilled intervention or support where these needs cannot practically be met by community nursing services.

58.5 Joint/coordinated CCG and LA reviews should be considered for any joint package in order to maximise effective care and support for the individual.

PG 59 Practice Example – Joint Package of Care

Jim is a 78-year-old man who has had a stroke. After rehabilitation he has residual weakness in his left arm and leg. He can manage the one step into and out of his ground floor property and is able to walk independently and safely around his home with a tripod walking stick. He gets in and out of his bed and armchair independently.

Jim can walk to his local shop (about 100 metres) in good weather but needs to stop frequently for short rests. For longer journeys he uses a wheelchair.

Jim has reduced dexterity of fine motor movements in his hand but is able to hold his stick securely. He has difficulty with buttons and zips. He is able to wash his predominantly affected side but finds it difficult and occasionally painful to wash his other side. He can manage his own toilet needs and has adapted clothing to manage his difficulty with zips and buttons.

Jim's main problem is that his speech and swallowing have not fully recovered and he is advised not to take food by mouth. He therefore has a peg feed fitted and receives four bolus feeds a day. He chooses to have tasters of food – two to three teaspoons at his breakfast and evening meal times. The dietician has given detailed instruction on the food consistency, the portion size and how he is to have these tasters.

Jim is realistic about his needs and faithfully follows the instructions about his food intake. Between meals he uses foam applicators to cleanse his mouth with cool water. Jim has no behavioural or cognitive problems, though he becomes upset at times when he reflects on his current health condition.

On assessment it was agreed that Jim does not have a primary health need, but, due to the risks to health associated with his particular needs, it was considered appropriate to

provide him with a joint package of care. His daily care package comprises:

a) half an hour social care (LA funded) each morning to help with dressing and showering

b) one-and-a-half hours health care (NHS funded) each morning for:

- preparation of appropriate consistency food and to observe Jim while he enjoys his tasters
- encouraging the correct double swallow prescribed by the speech therapist
- bolus feeding and liquid paracetamol via his peg which requires regular checking and monitoring
- observing him for thirty minutes as he had on some occasions posited back small amounts of the diet. This needs no intervention other than to assist him to expectorate or take appropriate emergency action if needed. Also to report all extended coughing episodes to the district nurse

c) one hour healthcare at lunch for bolus feed and medication

d) one-and-a-half hours healthcare in the early evening for bolus feed and medication

e) one hour healthcare late evening for bolus feed and medication

f) half an hour social care each evening for personal care.

In addition Jim receives four hours social care (LA funded) per week for shopping, banking, socialisation, etc. when care staff accompany him, push him in his wheelchair, and provide him with assistance in making himself understood. Jim also has one hour social care per week for housework and laundry. He employs someone privately to do his ironing, windows and small garden area, as this is his choice.

N.B. this division of responsibilities reflects what was locally agreed. Different models of sharing responsibility may be possible.

PG 60 Does NHS-funded Nursing Care cover the entire cost of a person's nursing needs?

- 60.1 No, it covers a contribution towards the cost of services provided by a registered nurse, involving either the provision of care or the planning, supervision or delegation of the provision of care, but it does not cover services which do not need to be provided or supervised by a registered nurse.
- 60.2 CCGs are reminded that joint funding will be appropriate where someone in a care home with nursing has nursing or other health needs that, whilst not constituting a primary health need, are clearly above the level of needs intended to be covered by NHS-funded nursing care.
- 60.3 Individuals in receipt of either NHS-funded nursing care or NHS continuing healthcare continue to be eligible for the full range of services available to any other patient of the

CCG, including specialist nursing services where required.

PG 61 In a joint package does the DST define which elements are the responsibility of the NHS and which are the responsibility of social services?

- 61.1 No. The completed DST will help to indicate the nature and levels of need of an individual, but it does not attribute responsibility for individual elements of a care package. Where a person is not entitled to full NHS continuing healthcare the cost of a jointly funded support package are a matter of negotiation between the CCG and the local authority based on the assessed needs of the person and the limits of what a local authority can fund.
- 61.2 One approach to identifying respective funding responsibilities is to analyse a 24 hour/48 diary of the tasks and interventions required to meet the individual's needs in order to identify which elements are beyond local authority powers, which are areas where both health and social care have power to provide, and which areas which are clearly social care responsibility.
- 61.3 CCGs and local authorities should agree protocols for dealing with jointly funded packages/placements. Local dispute resolution processes should cover both disputes over joint funding as well as NHS continuing healthcare eligibility.

PG 62 How does NHS-funded nursing care affect other funding for the care package such as from local authorities?

- 62.1 The fundamental issue here is about how the care home fee is shared between the NHS, the nursing home resident and/or the local authority.
- 62.2 NHS-funded nursing care is a contribution towards the cost of registered nursing in a care home.
- 62.3 The Care Home provider should set an overall fee level for the provision of care and accommodation. This should include any registered nursing care provided by them. Where a CCG assesses that the resident's needs require the input of a registered nurse they will pay the NHS-funded nursing care payment (at the nationally agreed rate) direct to the care home, unless there is an agreement in place for this to be paid via a 3rd party (e.g. a local authority). The balance of the fee will then be paid by the resident, their representative or the local authority unless other contracting arrangements have been agreed.

PG 63 Is there a national tool for assessing NHS-funded nursing care?

- 63.1 Annex C of the NHS-funded Nursing Care Practice Guide (revised) 2009 contains a template for recording nursing care needs. This template is for use in those situations where the individual has not already had a full MDT assessment with a DST completed (i.e. the individual has had a Checklist completed but this did not indicate the need for a full assessment for NHS continuing healthcare).

63.2 Where a full MDT assessment and DST have been completed there should be sufficient information to determine the need for NHS-funded nursing care.

PG 64 What is the relationship between NHS continuing healthcare and section 117 after-care under the Mental Health Act?

64.1 Services for needs that fall to be met as after-care services under section 117 of the Mental Health Act 1983 should be provided under that legislation rather than as NHS continuing healthcare. Only needs that are not section 117 after-care needs should be considered for NHS continuing healthcare eligibility in the usual way. For example, the individual might have or develop physical health needs which are distinct from the section 117 needs, and which separately constitute a primary health need. There should be no charge to the individual for section 117 services, regardless of whether they are being funded by a CCG or an LA.

64.2 LAs and CCGs should have agreements in place detailing how they will carry out their section 117 responsibilities, and these agreements should clarify which services fall under section 117 and which authority should fund them. LAs and CCGs may use a variety of different models and tools as a basis for working out how section 117 funding costs should be apportioned. However, where this results in a CCG fully funding a section 117 package this does not constitute NHS continuing healthcare.

64.3 It is preferable for the CCG to have separate budgets for funding section 117 and NHS continuing healthcare. Where they are funded from the same budget they still continue to be distinct and separate entitlements.

PG 65 Is there any additional guidance on the relationship between NHS continuing healthcare and the Mental Health Act 1983?

65.1 Arrangements under the **Mental Health Act** are separate and different from NHS Continuing Healthcare and the two should not be confused. The above guidance particularly deals with Section 117, however the same principle (regarding the need to determine whether the services are provided under the Mental Health Act or under NHS continuing healthcare) applies where an individual is subject to Section 17 leave or to a Section 17A Supervised Community Treatment Order.

PG 66 Do we make NHS-funded nursing care payments for section 117 patients placed in nursing homes?

66.1 Yes. See The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012.

PG 67 Is it necessary to complete a full Checklist and Decision Support Tool (DST) when carrying out a routine / annual review of NHS-funded nursing care ?

67.1 The NHS-funded Nursing Care Practice Guidance makes it clear that a Checklist should be carried out as part of a routine review of NHS-funded nursing care. Where the Checklist indicates that a full DST should be completed then an MDT should complete a full DST with the following exception. A DST will not be required where:

- the person has previously had a positive checklist and full DST completed by an MDT and
- there has been no material change in their needs that might lead to a different eligibility decision regarding NHS continuing healthcare and (by implication) NHS-funded nursing care

67.2 In order to determine this, the previously completed DST must be available at the NHS –funded nursing care review and each of the domains and previously assessed need levels considered as part of the review by the reviewer, in consultation with the person being reviewed and any other relevant people who know the person who are present at the review. The reviewer should annotate and sign each domain to indicate they have been considered, indicating any changes in need levels.

67.3 When notifying the person of the outcome of the review they should be advised that they have been assessed as meeting the Checklist threshold but that a full DST has not been completed because there has been no significant change in their need levels. A copy of the annotated DST should be given to the person concerned with information as to how they can request a review of the outcome of the NHS-funded nursing care review.

67.4 Where there has not been a previous DST completed by an MDT or where the NHS-funded nursing care review indicates a possible change in eligibility, a positive Checklist should always be followed by an MDT completed DST and a recommendation on eligibility regarding NHS continuing healthcare.

PG 68 There are two different kinds of dispute that may arise in relation to NHS continuing healthcare:

68.1 a) Disputes between a CCG and an LA regarding eligibility (which could also have additional complications arising from the two organisations being from different geographical areas).

b) Challenges (including requests for reviews) by the individual or their representative in relation to the process or decisions made.

68.2 On some occasions CCGs may receive requests for an independent review or other challenge from a close relative, friend or other representative who does not have LPA or deputy status. Where the individual has capacity, the CCG should ask them whether this request is in accordance with their instructions, and where they do not have capacity, a best interests process should be used to consider whether to proceed with the request for an independent review or other challenge.

PG 69 What issues should be considered at the Checklist stage of the decision-making process to avoid or resolve disputes?

- 69.1 The advice set out in the user notes for the Checklist addresses many of the key issues that may arise in its completion.
- 69.2 The Checklist has been intentionally designed to give a low threshold for passage through to the full eligibility consideration process. Therefore, provided that the Checklist has been completed by an appropriate health or social care professional, recommendations within Checklists should usually be accepted and actioned by CCGs.
- 69.3 Where an individual or their representative wishes to challenge a Checklist outcome, they should contact the relevant CCG, using the contact information supplied with the written decision. The CCG should give this request prompt and due consideration, taking account of all the information available, including any additional information from the individual or carer. The response should be given in writing as soon as possible. If the individual remains dissatisfied, they can ask for the matter to be considered under the NHS complaints procedure. Details of how to do this should be included with the written decision. At any stage, the CCG may decide to arrange for another Checklist to be completed or to undertake the full DST process, notwithstanding the outcome of the original Checklist.

PG 70 What issues should be considered at the DST stage of the decision-making process to avoid or resolve disputes?

- 70.1 The advice set out in the user notes for the DST addresses many of the key issues that may arise in its completion, such as the approaches to take when MDT members cannot agree on individual domain levels.
- 70.2 By practitioners working in partnership, and by following this guidance, it should be possible to resolve many disagreements regarding eligibility recommendations through the normal MDT process without the need to invoke formal dispute resolution procedures. However, the Standing Rules require each CCG and LA to have a jointly agreed disputes resolution process (in relation to both eligibility for NHS continuing healthcare and joint funding arrangements).
- 70.3 Where agreement cannot be reached through the normal eligibility decision-making processes, the formal dispute resolution process should be followed.
- 70.4 Where an individual and/or their representative expresses concern about any aspect of the MDT or DST process, the CCG coordinator should discuss this matter with them and seek to resolve their concerns. Where the concerns remain unresolved, these should be noted within the DST so that they can be brought to the attention of the CCG making the final decision.

PG 71 What factors need to be considered in local disputes processes?

- 71.1 It is important that local disputes processes include levels of escalation of the disputes, for example, by the matter initially being considered further by team managers from the CCG and LA and then increasing to senior management involvement as necessary. Disputes processes should also include a level by which the matter has to be finally resolved, even if it has not been resolved at lower levels. This could, for example, be by the matter being referred jointly to another CCG and LA, and agreeing to accept their recommendation. CCGs and LAs should carefully monitor the use of their disputes process. Disputes should be reviewed after resolution for learning points and these should be fed back to those involved in the decision-making process in the case and also built into the training of MDT members as appropriate.

PG 72 What if the dispute crosses CCG/LA borders?

- 72.1 Where a dispute occurs between a CCG and LA in different areas (and therefore without a shared disputes resolution agreement) it is recommended that the local process applying to the CCG involved in the case is used. Where a dispute involves two CCGs, it is recommended to use the disputes process for the CCG area where the individual is residing at the outset of the relevant decision-making process. Thus if CCG A had made a placement in CCG B's area, it is CCG A's dispute process that should be used, even if the person is now physically residing in CCG B's area. Both CCGs should be able to play a full and equal role in the dispute resolution. Consideration could be given to identifying an independent person (who is not connected with either CCG) to oversee the resolution of the dispute. CCGs and LAs should consider agreeing and publishing local processes and timescales for responding to complaints and concerns relating to NHS continuing healthcare on issues that fall outside of the IRP process.

PG 73 What if the individual wishes to challenge the final eligibility decision made by the CCG?

- 73.1 If the individual or their representative wishes to dispute the decision made and/or the process used to reach it, they can request an independent review through the Board as set out in this Framework. However, CCGs should always work with the individual and their representatives to seek to resolve the matter informally without the need for an IRP. Even when an IRP has been requested, CCGs should continue to seek to informally resolve the matter, up to the date of the IRP hearing itself. When the Board receives an IRP request they should contact the relevant CCG to establish what efforts have been made to achieve local resolution and the outcome. The Board can consider asking CCGs to attempt further local resolution prior to the IRP hearing. CCGs and the Board may receive requests that are outside the remit of the IRP process (i.e. that are not about the application of the eligibility criteria or the process followed to reach the decision). The eligibility criteria are set nationally by Standing Rules and so are not a matter for local review or complaints processes. If CCGs and the Board receive review requests about other non-IRP matters (for example, the nature of the care package to be provided) they should advise the individual to pursue the matter through the NHS complaints process. CCGs should consider publishing local processes and timescales for responding to complaints and concerns relating to NHS continuing healthcare on

issues that fall outside of the IRP process.

PG 74 What can key agencies do to improve partnership working in relation to NHS continuing healthcare?

74.1 NHS continuing healthcare can only be delivered successfully through a partnership approach at both organisational and practitioner levels between the Board, CCGs, LAs, local NHS bodies, and provider organisations. Local protocols covering the areas where agreement is needed on policy and processes relevant to NHS continuing healthcare may be helpful in ensuring consistency and developing relationships. Annex G contains guidelines on what could be included in such protocols. Trust between organisations is developed by actions that are trustworthy and transparent, and by an approach that is based on everyone seeking to accurately apply the eligibility criteria rather than seeking to move responsibility to another organisation. Amongst other things good partnership working involves:

- The Board, CCGs and LAs, as far as possible, adopting similar approaches to the ranges and models of care/support they commission so that there is no perceived advantage or disadvantage to being funded by one agency rather than the other
- The Board, CCGs and LAs developing similar approaches to risk and enablement
- The Board, CCGs, LAs and providers supporting their staff to adopt creative, flexible approaches that reflect best practice
- Practitioners across all sectors being supportive, open and honest with one another
- Practitioners respecting each other's professional judgement, knowledge and experience and working together to obtain the best outcome for the individual
- Dealing with genuine disagreements between practitioners in a professional manner without inappropriately drawing the individual concerned into the debate in order to gain support for one professional's position or the other
- Practitioners being clear with each other what services can be commissioned by their respective organisations in order to give accurate information to the individuals concerned.

74.2 Examples of good partnership working include:

- the LA and CCG having unified commissioning/contracting arrangements, with one organisation commissioning and/or contracting on behalf of both
- joint brokerage arrangements between the LA and CCG
- joint preparation and delivery of training
- joint arrangements for hospital discharge coordinators funded by the CCG based in acute hospitals to ensure good communication, correct processes and to streamline

decision-making

- reciprocal agreements around 'funding without prejudice'
- joint tendering for domiciliary care
- Secondment/joint post arrangements whereby social care staff work alongside CCG staff to undertake NHS continuing healthcare assessments
- Arrangements to jointly review those receiving NHS continuing healthcare
- CCGs working with the Transition Team to ensure screening and planning occurs for young people approaching adulthood who may become eligible for NHS continuing healthcare
- Appointment of a social worker within an NHS continuing healthcare team
- Joint funding of advocacy services by CCGs and LAs

PG 75 What is the role of the CCG in relation to NHS continuing healthcare?

75.1 CCGs have the lead responsibility for NHS continuing healthcare in their locality (but there are also specific requirements for LAs to cooperate and work in partnership with them in a number of key areas). In addition CCGs need to have clear arrangements with other NHS organisations (e.g. Foundation Trusts) and independent/ voluntary sector partners to ensure effective operation of the Framework.

75.2 Paragraphs 161 - 165 of this Framework set out best practice governance responsibilities of CCGs. These are expanded on below.

Ensuring consistency in the application of the national policy on eligibility for NHS continuing healthcare

This may be achieved, for example, through the CCGs:

- monitoring patterns of eligibility decision-making
- using monitoring data to identify and address variations between areas and client groups (including use of the equality monitoring forms)
- peer review of eligibility decisions
- management audits of practice
- developing consistent protocols around completion of the Decision Support Tool (DST)
- working with staff to disseminate learning from the above processes and to identify development issues
- providing effective equality, diversity and human rights training and development, with a particular emphasis on understanding the cultures of the people they are most likely to encounter in their local area.

Promoting awareness of NHS continuing healthcare

This may be achieved, for example, through:

- ensuring that public information is available in appropriate formats and languages at key locations
- providing up to date information on the CCG and LA websites
- providing awareness raising sessions for staff
- using existing networks to promote better understanding of NHS continuing healthcare
- working with independent and/or voluntary organisations to promote awareness.

Implementing and maintaining good practice

This may be achieved, for example, through:

- clinical supervision arrangements with staff both individually and as a team
- ensuring that training is jointly developed and delivered with LA partners and tailored to identify and promote good practice
- use of regional meetings to identify and promote good practice and consistency
- use of pathway/process analysis to identify areas for development.

Ensuring that quality standards are met and sustained

This could, for example, include:

- agreement of quality standards across key agencies
- monitoring contracts for delivery of delegated NHS continuing healthcare functions
- use of auditing tools to check process and quality at different stages
- learning from complaints/compliments.

Providing training and development opportunities for practitioners

The CCG's responsibility is to maintain an oversight as to whether staff across relevant agencies are appropriately trained in relation to NHS continuing healthcare, though this does not necessarily mean the CCG has to carry out or fund all the training itself. The CCG's actions could, for example, include:

- providing core training courses on a rolling programme, jointly developed and delivered with other NHS organisations and the LA
- providing specialist training sessions for coordinators/nurse assessors/social workers and others in NHS continuing healthcare roles across organisations
- ensuring training is available for relevant independent sector provider staff
- making training materials available for other organisations to use
- inclusion of NHS continuing healthcare in induction training for all relevant staff.

Identifying and acting on issues arising in the provision of NHS continuing healthcare

This could, for example, include:

- systematically reviewing complaints and disputes, including looking for patterns of unlawful discrimination or disproportionate negative impact on individuals, groups and communities
- undertaking 'root cause analysis' when a problem arises
- addressing the issues through contract management processes with provider organisations
- using some form of 'joint solutions group' with the LA
- establishing robust risk management systems
- being a 'learning organisation' so that the whole team discusses and identifies necessary practice changes.

Informing commissioning arrangements, both on a strategic and an individual basis

The key to high quality cost-effective care is through robust commissioning and contracting arrangements. Achieving this could, for example, involve:

- use of activity and other monitoring data together with information from individual assessments and joint strategic needs assessments to forecast future patterns of demand
- joint analysis of needs with the LA through strategic needs analysis processes
- a coordinated approach between the LA and CCG at all levels of commissioning, brokerage and purchasing to provide a single and coherent interface with the market
- consideration of regional commissioning for cost-effective specialist provision, though care needs to be taken to ensure models that enable personalisation and choice, particularly for socially excluded, vulnerable and hard to reach groups
- liaising with local providers and providing information about likely future demand, possibly through a joint provider forum with the relevant LA and by having an identified CCG lead for liaison with providers.

PG 76 What is the role of the LA in NHS continuing healthcare?

- 76.1 The Standing Rules require CCGs to consult, so far as is reasonably practicable, with the relevant social services authority before making a decision on a person's eligibility for NHS continuing healthcare. (The Ordinary Residence Guidance 2011⁴¹ should be used to identify the relevant social services authority.)
- 76.2 Social services authorities shall provide advice and assistance to a CCG over individual cases as far as reasonably practicable. This duty applies regardless of whether a community care assessment is needed and is separate from the LA's duty to carry out assessments under section 47 of the NHS and Community Care Act 1990.

⁴¹ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_126003

76.3 However, once such a case has been brought to the attention of the social services authority, in addition to giving advice and assistance it should, having regard to the facts of the case, also consider whether a community care assessment is required. Where community care assessments have been carried out, the LA should use information from these assessments to assist the CCG in carrying out its responsibilities.

76.4 The roles that a LA should undertake as part of this duty include:

- making staff available wherever practicable to be part of multidisciplinary teams (MDTs) which will undertake joint assessments and jointly complete the DST (including where the individual is a self-funder)
- contributing to eligibility panels (where these exist) and participating in the decision-making process on eligibility
- making staff available to undertake joint reviews
- having systems for responding promptly to requests for information when the CCG has received a referral for NHS continuing healthcare
- working jointly with the CCG in the planning and commissioning of care/ support for individuals deemed eligible for NHS continuing healthcare wherever appropriate, sharing expertise and local knowledge (whilst recognising that CCGs retain formal commissioning and care planning responsibility for those eligible for NHS continuing healthcare).

76.5 LAs shall make nominations to the Board of potential members of Independent Review Panels (IRPs) whenever requested by the Board and, where appointed, to make their nominees available to participate in IRPs as far as reasonably practicable.

PG 77 What information is available to give to members of the public about NHS continuing healthcare?

77.1 A public information leaflet⁴², entitled 'NHS continuing healthcare and NHS-funded nursing care' is available. CCGs should make these available to members of the public, for example through local NHS websites, hard copies on hospital wards, through primary care outlets, local care homes and local voluntary sector organisations. Any individual being considered for NHS continuing healthcare at the Checklist stage should be given a copy of the leaflet along with any relevant local information about processes and contact arrangements.

PG 78 How should care planning be approached for a person entitled to NHS continuing healthcare?

78.1 It is important that the services commissioned and provided for a person in receipt of NHS continuing healthcare are based on supporting the outcomes identified in a care plan jointly developed and agreed with the individual and regularly updated and reviewed. There should therefore be strong linkages between the care planning and

⁴² <http://www.dh.gov.uk/health/2012/11/continuing-healthcare-revisions/>

commissioning processes in CCGs.

78.2 Supporting People with Long-Term Conditions; Commissioning Personalised Care Planning. A Guide for Commissioners sets out how to adopt a personalised approach for individuals with a long-term condition and how to reflect this in the commissioning of services. Clearly most people who are eligible for NHS continuing healthcare have a long-term condition or other long-term health need. Even for those who qualify for other reasons, the approaches in the guidance are still applicable. It sets out that the care planning process:

- puts the individual, their needs and choices that will support them to achieve optimal health and well-being at the centre of the process
- focuses on goal setting and outcomes that people want to achieve, including carers
- is planned, anticipatory and proactive with contingency planning to manage crisis episodes better
- promotes choice and control by putting the person at the centre of the process and facilitating better management of risk
- ensures that people, especially those with more complex needs, the socially excluded and particularly vulnerable or those approaching the end of life, receive coordinated care packages, reducing fragmentation between services
- provides information that is relevant and timely to support people with decision-making and choices
- provides support for self care so that people can self care/self manage their condition(s) and prevent deterioration
- facilitates joined-up working between different professions and agencies, especially between health and social care, and
- results in an overarching, single care plan that is owned by the person but can be accessed by those providing direct care/services or other relevant people as agreed by the individual, e.g. their carer(s). The important aspect of this is that the care planning discussion has taken place with an emphasis on goal setting, equal partnership, negotiation and shared decision-making.

78.3 There are other models of personalised care planning using similar approaches which could also be used when appropriate.

PG 79 Who is responsible for equipment and adaptations if someone is eligible for NHS continuing healthcare and is in their own home?

79.1 The focus of NHS continuing healthcare should be on enabling the delivery of the desired outcomes of the individual and promoting their physical and psychological well-being. Care planning should therefore consider the need for equipment to assist with activities of daily living and the provision of healthcare, personal care, social care support and wider housing adaptation needs.

79.2 As set out in the Framework (paragraph 172), those in receipt of NHS continuing healthcare should have access to local joint equipment services on the same basis as any other patient of their CCG. Local agreements on the funding of joint equipment services should take into account the fact that the NHS has specific responsibilities for meeting the support needs of those entitled to NHS continuing healthcare. Some

individuals will require bespoke equipment (and/or specialist or other non-bespoke equipment that is not available through joint equipment services) to meet specific assessed needs identified in their NHS continuing healthcare care plan. CCGs should make appropriate arrangements to meet these needs.

- 79.3 For larger adaptations, Disabled Facilities Grants (DFGs) may be available from local housing authorities towards the cost of housing adaptations that are necessary to enable a person to remain living in their home (or to make a new home appropriately accessible). DFGs are means-tested. However, housing authorities, CCGs and LA social services authorities all have discretionary powers to provide additional support where appropriate. Further details can be found in the guidance *Delivering Housing Adaptations for Disabled People; A Good Practice Guide*⁴³. This guidance encourages the above bodies, together with home improvement agencies and registered social landlords, to work together locally on integrated adaptations services. Whether or not such integrated services are in place, CCGs should consider having clear arrangements with partners setting out how the adaptation needs of those entitled to NHS continuing healthcare should be met, including referral processes and funding responsibilities.
- 79.4 CCGs should be aware of their responsibilities and powers to meet housing-related needs for those entitled to NHS continuing healthcare:
- a) CCGs have a general responsibility under section 3(1)(e) of the NHS Act 2006 to provide such after-care services and facilities as it considers appropriate as part of the health service for those who have suffered from illness.
 - b) The Board has responsibility for arranging, under section 3B(1) of the NHS Act 2006 and under Standing Rules Regulations, secondary care and community services for serving members of the armed forces and their families, and prisoners, as part of the health service to such an extent as it considers necessary to meet all reasonable requirements.
 - c) CCGs may make payments in connection with the provision of housing to housing authorities, social landlords, voluntary organisations and certain other bodies under sections 256 and 257 of the above Act.
 - d) CCGs also have a more general power to make payments to LAs towards expenditure incurred by the LA in connection with the performance of any LA function that has an effect on the health of any individual, has an effect on any NHS function, is affected by any NHS function or are connected with any NHS function.
 - e) Housing can form part of wider partnership arrangements under section 75 of the above Act.
- 79.5 LAs should be aware that they may continue to have responsibilities under section 47 of the NHS and Community Care Act 1990 and under section 2 of the Chronically Sick and Disabled Persons Act 1970 to those in receipt of NHS continuing healthcare. However, in deciding whether it is necessary to provide services under these provisions the LA should take into account services that are/will be provided by the NHS, either as NHS

⁴³ <https://www.gov.uk/government/publications/delivering-housing-adaptations-for-disabled-people>

continuing healthcare or as other NHS services. They may also continue to have some responsibilities for those in their own homes entitled to NHS continuing healthcare where the services needed are not ones that the Secretary of State requires the NHS to provide. This can include support for housing-related needs where appropriate. When carrying out an assessment for a property adaptation or the provision of equipment for someone receiving NHS continuing healthcare funding, LAs should respond positively to requests for a community occupational therapy assessment to assist and advise the individual and the CCG on deciding on appropriate equipment/adaptation and whether or not the adaptation is necessary to meet the assessed NHS continuing healthcare needs.

- 79.6 Whilst LAs and CCGs have some overlapping powers and responsibilities in relation to supporting individuals eligible for NHS continuing healthcare in their own home, a reasonable division of responsibility should be negotiated locally. In doing this, CCGs should be mindful that their responsibility under NHS continuing healthcare involves meeting both health and social care needs based on those identified through the MDT assessment. Therefore, whilst LAs and CCGs have overlapping powers, in determining responsibilities in an individual case, CCGs should first consider whether the responsibility to meet a specific need lies with them as part of their NHS continuing healthcare responsibilities. LAs should be mindful of the types of support that they may provide in such situations as outlined in PG85 below.

PG 80 Case management

- 80.1 Once an individual has been found eligible for NHS continuing healthcare, the CCG is responsible for their case management, including monitoring the care they receive and arranging regular reviews. This could be through joint arrangements with LAs, subject to local agreement. CCGs should ensure arrangements are in place for an ongoing case management role for all those entitled to NHS continuing healthcare, as well as for the NHS elements of joint packages.
- 80.2 Case management should be person-centred. The individual should be encouraged to have an active role in their care, be provided with information or signposting to enable informed choices, and supported to make their own decisions.
- 80.3 In the context of NHS continuing healthcare case management necessarily entails management of the whole package, not just the healthcare aspects. The key elements of the role include:
- a) ensuring that a suitable care plan has been drawn up for and with the individual in line with the approaches set out in PG 78 above – this might best be done initially by the MDT involved in their care, in consultation with the person concerned or their representative
 - b) ensuring that the care/support package meets the individual's assessed needs and agreed outcomes and is appropriate to achieve the identified intended outcomes in the care plan
 - c) where the care plan includes access to non-NHS services, for example leisure

services, ensuring that the arrangements for these are in place and are working effectively

d) monitoring the quality of the care and support arrangements and responding to any difficulties/concerns about these in a timely manner

e) acting as a link person to coordinate services for the individual

f) ensuring that any changes in the person's needs are addressed

g) reviewing the situation on a regular planned basis, and if necessary undertaking additional unplanned reviews where circumstances require. Reviews need to consider not just whether the individual is still eligible for NHS continuing healthcare but also the effectiveness and appropriateness of the care/support arrangements.

PG 81 How should commissioning be approached for a person entitled to NHS continuing healthcare?

81.1 This Framework sets out a number of responsibilities of CCGs in relation to NHS continuing healthcare commissioning:

a) NHS continuing healthcare commissioning involves actions at both strategic and individual levels.

b) NHS continuing healthcare commissioning actions by CCGs should include strategic planning, specifying outcomes, procuring services, and managing demand and provider performance (including monitoring quality, access and the experience of those in receipt of NHS continuing healthcare). In managing the quality and performance of providers and the experiences of those using their services, CCGs should take into account the role and areas of focus of the Care Quality Commission and, where relevant, LA commissioners of the relevant provider's services in order to avoid duplication and to support the mutual development of an overall picture of each provider's performance.

c) There should be clarity on the roles of commissioners and providers. The services commissioned should include an ongoing case management role as well as the assessment and review of individual needs.

d) CCGs should consider commissioning from a wide range of providers in order to secure high quality, value for money services. In exercising this responsibility, CCGs should have regard to the case management role set out in 11.4 above of ensuring that the care/support package meets the individual's assessed needs and agreed outcomes and is appropriate to achieve the identified intended outcomes in the care plan. To help inform this approach, CCGs should have an understanding of the market costs for care and support within the relevant local area.

e) CCGs should commission in partnership with LAs wherever appropriate.

f) CCGs should ensure clarity regarding the services being commissioned from providers, bearing in mind that those in receipt of NHS continuing healthcare continue to

be entitled to access the full range of primary, community, secondary and other health services. The services that a provider of NHS continuing healthcare-funded services is expected to supply should be clearly set out in the contract between the provider and the CCG. CCGs 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. CCGs should also be aware of the personal health budgets programme as set out in Personal Health Budgets: First Steps⁴⁴ and particularly that it is only direct payments that will be restricted to approved pilots. The other models of personal health budgets are available under existing powers for any CCG to use.

g) CCGs 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.

h) CCGs should take into account other policies and guidance relevant to the individual's needs.

PG 82 Can a CCG use an external agency to carry out the commissioning of NHS continuing healthcare services or for negotiation with providers?

82.1 CCGs hold the statutory responsibility for commissioning NHS services for their populations, including NHS continuing healthcare. The Board hold statutory responsibility for commissioning certain services for serving members of the armed forces and their families, and prisoners. Whilst the Board and CCGs may reach arrangements with other organisations to carry out functions on their behalf, they retain statutory responsibility. The Board and CCGs can make arrangements with LAs or other bodies/organisations in relation to NHS continuing healthcare commissioning. In order for the LA to commission NHS continuing healthcare on the Board's or CCG's behalf, this requires a transfer of appropriate powers using section 75 of the NHS Act 2006. Other arrangements, such as integrated teams of the Board or CCG and LA staff commissioning for individuals with high support needs in an integrated manner are also possible. In all cases, the Board or CCGs retain ultimate responsibility for NHS continuing healthcare commissioning. Any such arrangements should reflect the Board or CCG's responsibilities to fund the assessed health and social care needs of individuals entitled to NHS continuing healthcare and that NHS continuing healthcare, as with most other NHS services, is free at the point of delivery to the individual.

82.2 The Board and CCGs should ensure that there is clarity in arrangements with external organisations on the respective responsibilities of the Board or CCG and of the external organisations in relation to the above roles. The approaches of the external organisation to the functions they carry out on behalf of the Board or CCG should reflect the best practice set out for the Board and CCGs in this practice guidance and in the Framework. The external organisation should operate within the Board's or CCG's strategic

⁴⁴ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093842

approaches and policies in relation to NHS continuing healthcare commissioning including in relation to the range of providers and the choice available to individuals.

PG 83 What limits (if any) can be put on individual choice where, if followed, this would result in a CCG paying for a very expensive care arrangement? Under what circumstances can a CCG decline to provide care in the preferred setting of the individual?

- 83.1 This Framework says (paragraph 167) that ‘the package to be provided is that which the CCG assesses is appropriate for the individual’s needs’.
- 83.2 In many circumstances there will be a range of options for packages of support and their settings that will be appropriate for the individual’s needs. The starting point for agreeing the package and the setting where NHS continuing healthcare services are to be provided should be the individual’s preferences. Individuals will not always be aware of the models of support that it is possible to deliver (for example, they may assume that it is only possible to receive support in a care home). Those involved in working with individuals to plan their future support should advise them of the options and the benefits and risks associated with each one. CCGs should be aware of the models of support offered by partners and in the case of CCGs, by other CCGs, and of evidence about their benefits and risks so that the options offered are maximised and that generalised assumptions are avoided.
- 83.3 In some situations a model of support preferred by the individual will be more expensive than other options. CCGs can take comparative costs and value for money into account when determining the model of support to be provided but should consider the following factors when doing so:
- a) The cost comparison has to be on the basis of the genuine costs of alternative models. A comparison with the cost of supporting a person in a care home should be based on the actual costs that would be incurred in supporting a person with the specific needs in the case and not on an assumed standard care home cost.
 - b) Where a person prefers to be supported in their own home, the actual costs of doing this should be identified on the basis of the individual’s assessed needs and agreed desired outcomes. For example, individuals can sometimes be described as needing 24-hour care when what is meant is that they need ready access to support and/or supervision. CCGs should consider whether models such as assistive technology could meet some of these needs. Where individuals are assessed as requiring nursing care, CCGs should identify whether their needs require the actual presence of a nurse at all times or whether the needs are for qualified nursing staff or specific tasks or to provide overall supervision. The willingness of family members to supplement support should also be taken into account, although no pressure should be put on them to offer such support. CCGs should not make assumptions about any individual, group or community being available to care for family members.
 - c) Cost has to be balanced against other factors in the individual case, such as an individual’s desire to continue to live in a family environment (see the Gunter case in box below).

PG 84 Gunter Case

84.1 In the case of *Gunter vs. South Western Staffordshire Primary Care Trust (2005)*, a severely disabled woman wished to continue living with her parents whereas the PCT's preference was for her to move into a care home. Whilst not reaching a final decision on the course of action to be taken, the court found that Article 8 of the European Convention of Human Rights had considerable weight in the decision to be made, that to remove her from her family home was an obvious interference with family life and so must be justified as proportionate. Cost could be taken into account but the improvement in the young woman's condition, the quality of life in her family environment and her express view that she did not want to move were all important factors which suggested that removing her from her home would require clear justification.

PG 85 What are the responsibilities of CCGs and LAs when a person is supported in their own home?

85.1 Where someone is assessed as eligible for NHS continuing healthcare but chooses to live in their own home in order to enjoy a greater level of independence, the expectation in the Framework is that the CCG would remain financially responsible for all health and personal care services and associated social care services to support assessed health and social care needs and identified outcomes for that person, e.g. equipment provision (see PG 79), routine and incontinence laundry, daily domestic tasks such as food preparation, shopping, washing up, bed-making, support to access community facilities, etc. (including additional support needs for the individual whilst the carer has a break). However, people who choose to live in their own home may have additional community care needs which it may be appropriate for the LA to address subject to their local eligibility threshold and charging policy, e.g. assistance with property adaptation (see PG 79), support with essential parenting activities, support to access other community facilities, carer support services that may include additional general domestic support, or indeed any appropriate service that is specifically required to enable the carer to maintain his/her caring responsibilities (bearing in mind PG 89 below).

85.2 There is a range of circumstances in which CCGs have overlapping powers with other statutory organisations. Where this is the case, CCGs and other statutory bodies should work in partnership locally to determine how each partner's responsibilities will be exercised. CCGs should not simply assume that another organisation will meet the need. Active liaison should take place. The needs appropriate for the CCG to meet will depend upon the circumstances of the individual case, having regard to the overall purpose of the health service – to improve physical or mental health, and to prevent, diagnose or treat illness.

85.3 Where other agencies/organisations have potentially overlapping powers/responsibilities there should be a discussion between the parties involved. If someone is receiving NHS continuing healthcare in their own home their benefits are unaffected (although they will not be able to receive support from the Independent Living Fund). There is a range of everyday household costs that are expected to be covered by personal income or through welfare benefits (i.e. food, rent/mortgage interest, fuel, clothing and other normal household items). In addition, disability-related benefits (e.g.

Disability Living Allowance and Attendance Allowance) are intended to cover some disability-related costs. As individual circumstances will differ considerably, it is not possible to give hard and fast rules on how best to divide responsibilities where overlapping powers exist. However, the following questions may help inform the decision-making process:

- a) Is this service part of the support plan necessary to meet the individual's assessed health, personal care and associated social care needs?
- b) What support is necessary for the CCG to fund/provide in order for the individual to access essential services?
- c) What responsibilities do other organisations/agencies have to enable the person to access essential services?
- d) What would happen if a CCG or a partner organisation did not fund/ provide the service in question – what would the outcome be?

PG 86 If a person is in receipt of NHS Continuing Healthcare are they entitled to any local authority funding for social care?

86.1 Local authorities may not provide community care services to anyone in a care home who gets NHS Continuing Healthcare, although they have a role in relation to their wider responsibilities such as safeguarding vulnerable adults and the Deprivation of Liberty Safeguards. Where an individual is in receipt of NHS Continuing Healthcare but is living in their own home the NHS is still responsible for meeting all nursing and personal care needs and associated social care needs but there may be other needs that the local authority can help with. For full details see PG 85 above.

PG 87 If someone receiving NHS Continuing Healthcare also receives some services from the local authority, will they be means tested and charged for these services?

87.1 The individual should not be charged for any NHS Continuing Healthcare service funded by the NHS. If a local authority is providing additional services it may use its powers to charge the individual subject to the person's financial circumstances and the local authority's Fairer Charging policy.

PG 88 If someone has NHS Continuing Healthcare at home, does the CCG have for pay rent/mortgage, food and utility bills?

88.1 No. The NHS is responsible for funding health and personal care costs, not rent, food and normal utility bills. There will be circumstances, however, when a contribution towards a utility bill may be appropriate (because, for example, the individual has increased costs to run specialised equipment).

PG 89 What is the CCG role in relation to carers when someone is in receipt of NHS continuing healthcare?

89.1 When a CCG decides to support a home-based package where the involvement of a family member/friend is an integral part of the care plan then the CCG should give consideration to meeting any training needs that the carer may have to carry out this role. In particular, the CCG may need to provide additional support to care for the individual whilst the carer(s) has a break from his/her caring responsibilities and will need to assure carers of the availability of this support when required. This could take the form of the cared-for person receiving additional services in their own home or spending a period of time away from home (e.g. a care home). Consideration should also be given to referral for a separate carer's assessment by the relevant LA.

PG 90 Can a personal health budget be used for people eligible for NHS continuing healthcare?

90.1 Yes, CCGs are encouraged to use personal health budgets where appropriate .A personal health budget helps people to get the services they need to achieve their health outcomes, by letting them take as much control over how money is spent on their care/support as is appropriate for them. It does not necessarily mean giving them the money itself. Personal health budgets could work in a number of ways, including:

- a notional budget held by the CCG commissioner
- a budget managed on the individual's behalf by a third party, and
- a cash payment to the individual (a 'healthcare direct payment').

90.2 Direct payments for healthcare can only currently be offered by the Board, or by CCGs that are pilot sites approved by the Secretary of State. However CCGs already have powers to offer other forms of personal health budgets, either as a notional budget or a real budget held by a third party.

Further details are given in Personal Health Budgets: First Steps.

PG 91 What information and advice is available regarding the development of personalised commissioning and personal health budgets?

91.1 A wide variety of resources are available via the personal health budgets learning network website at www.dhcarenetworks.org.uk/PHBLN/. This includes a range of resources to support personalised commissioning generally beyond personal health budgets. CCGs should also be aware that materials developed for LA social care personalisation and individual budgets include many principles which are also relevant to health services. These can be accessed through the above website. CCGs and LAs are encouraged to work closely together with regard to the personalisation of care and support in order to share expertise and develop arrangements that provide for smooth transfers of care where necessary.

PG 92 What practical examples are there of how someone with a primary health need can have their needs met through a 'notional health budget'?

- 92.1 John suffered a series of strokes beginning in his 60s, leading up to a serious stroke that resulted in vascular dementia. He spent some time in a nursing home but did not like it and moved to live with his daughter Susan when he was 77 years old.
- 92.2 Over time John became immobile and Susan (who was recovering from cancer, working part time and caring for her son) was unable to provide the necessary care alone. He was found to be eligible for NHS continuing healthcare funding and received a standard care/support package (four calls a day with two care workers at each call). Twice a week he also received a sitting service. Susan had to provide support at all other times. This placed significant stress upon her. She had no opportunity to go out with her son at all, and their relationship was suffering. She was also starting to suffer from depression.
- 92.3 Occasionally, as part of the care package John had respite care in a nursing home which he did not enjoy and on the second occasion came home in a 'sorry' condition. As a result of this his daughter cancelled the respite component of the package and her anxiety and feeling of helplessness increased.
- 92.3 Every time John was hospitalised the experience was very disorientating for him and distressing for his family. John had always been clear that he wanted to remain with his daughter and as his condition worsened this need became increasingly important to him.
- 92.4 By the following year John was in an advanced stage of vascular dementia and was totally reliant on others for his physical care needs, needing 24-hour support.
- 92.5 Susan reported being at 'breaking point'. Any changes in John's accommodation due to this would have been against his wishes of him wanting to live with her and detrimental to his mental well-being. Had care at home failed, this would have also damaged Susan's mental well-being further.
- 92.6 Susan agreed to take part in a local personalisation pilot with her CCG. A package was agreed that included a flexible allocation of £315 per week. Susan decided the extra funding was to be used for flexible care hours that she could 'bank' and use at her discretion. The regular care calls continued but the £315 was paid to the care provider by NHS Doncaster and between the provider and Susan, a system was set up that enabled Susan to use the hours flexibly. This covered her being away from the home for either work, parenting activities or respite. Every Saturday care was provided between 11am to 4pm to enable Susan to take her son out.
- 92.7 At this time John's communication was limited. However, Susan reported that when they did communicate she could tell that he knew and liked the circle of people who were looking after him and that he felt secure in their care when Susan was away from the home. Some of the informal tasks that Susan carried out like liaising with district nursing teams were taken over by the care provider and the team would contact the GP direct rather than interrupt Susan at her work.
- 92.8 After receiving his personal budget for two-and-a-half months, John died. His daughter

felt that the last two months of all their lives had been transformed beyond recognition and that John had died peacefully at home with his family as he had wished.

PG 93 What practical options are there for meeting the needs of someone eligible for NHS continuing healthcare by means of a 'real personal budget held by a third party'?

Practice Example – Real Personal Budget Held by Third Party

- 93.1 David has a learning disability and a history of challenging behaviour which in the past has resulted in multiple admissions to in-patient assessment and treatment services. He has epilepsy which has previously resulted in injury from falls, although this has been well controlled in recent years. He also has periodic difficulties with hand-eye coordination.
- 93.2 Three years ago, through working with a clinical psychologist and with support from an advocate, it was identified that David's challenging behaviour was primarily triggered by:
- frequent changes of staff and residents which increased David's anxiety levels
 - a lack of ability to regularly engage in sporting activities and walking. David enjoys doing these and they act as an important release valve that reduces behavioural issues. A risk assessment had identified a need for staff support when carrying out these activities due to David's epilepsy and challenging behaviour. However the staff from the care home where David then lived were part of a team supporting other residents so were not able to commit sufficient support to David for these activities
 - his hand-eye coordination resulting in difficulties in using his computer. David enjoys on-line computer games as the others on-line are unaware of his impairments, so he feels treated as an equal, which increases his self-esteem. However, when his coordination difficulties occur he gets frustrated.
- 93.3 David moved into a house which he shared with two other tenants whom he already knew and was happy to live with. The overall support came from a small team funded through Supporting People. The team find job satisfaction in working with a small number of residents and tend to remain in post long-term. David also received an LA direct payment for additional support which he used to employ a support worker with IT skills who both accompanied him in sport and walking and supported him with computer games when needed. There were no assessment and treatment admissions for three years.
- 93.4 David's epilepsy has recently become more unpredictable. He fell whilst walking and has had two hospital admissions. He has now been found eligible for NHS continuing healthcare. The CCG have advised that they cannot currently offer a direct payment for David's own personal support worker so alternative support arrangements will need to be put in place by the CCG. The housing support provider has also advised that they consider that David's epilepsy may be too great a risk for their staff to manage and so they may not be able to continue to support him.

- 93.5 A multidisciplinary review is held. The CCG funds an advocate for David to support him in the review. It is identified that Supporting People funding is not affected by NHS continuing healthcare entitlement so can continue in place. Arrangements are made for the CCG to train the support provider's staff in the triggers to look for in David's epilepsy and a protocol to follow, including a contact number for any concerns. It is agreed that the additional individual support is key to maintaining David's stable behaviour and his general health and well-being. The option of funding the support provider to employ David's personal support worker is discussed but David does not want this as he is concerned that they may get absorbed into the overall team and his individual support may be lost.
- 93.6 The LA advise on support providers used locally by those in receipt of LA individual budgets who have a good track record for working in an individualised way. The CCG, in liaison with David and his advocate, identify a support provider who is willing to take over the employment of David's personal support worker with funding from the CCG. A protocol is developed between the CCG, the support provider and David which states that David oversees the day-to-day activities of the support worker.

PG 94 Can the LA be an intermediary for a real personal health budget where the individual has been assessed as having a primary health need? If so, how?

- 94.1 CCGs taking part in the personal health budget pilots and LAs are encouraged to work together as much as possible to deliver joined-up services to individuals with personal health budgets. This includes making use of pooled budget and joint financing arrangements. However, it is important to remember that health and social care legislation explicitly prevents CCGs from passing health money over to LAs to use as an LA direct payment to purchase healthcare. Therefore, when deciding what the LA can do in relation to individuals with direct payments for healthcare, both organisations need to be very clear about their roles. Individual CCGs and LAs will need to come to their own decision on which method is most suitable for them, and seek their own legal advice as necessary.

PG 95 Can a local authority act as a 3rd party to administer direct payments to someone who has been deemed eligible for NHS Continuing Healthcare?

- 95.1 Where a CCG has been authorised to have powers to make NHS Direct Payments, they can reach a formal agreement (under Section 75 of the NHS Act 2006) to transfer these powers (and funding) to the relevant local authority. This would enable the local authority to make direct payments to individuals receiving NHS continuing healthcare.
- 95.2 Where an individual is not entitled to NHS continuing healthcare but is receiving a joint package of care between the LA and CCG, they can reach agreement for the local authority to make a direct payment for the elements of the care package that are within local authority powers. The remaining elements of the care package (beyond local authority powers) should be arranged by the CCG in a manner that, as far as possible, is compatible with the direct payment arrangements.
- 95.3 Where the CCG has not been given powers to offer direct payments, there is currently

no provision to allow a local authority to make direct payments for NHS continuing healthcare on their behalf. However, the CCG should always consider the other models of personal health budget that are available for all CCGs to use, including a) notional personal health budget held by the CCG and used in partnership with the individual; and b) a real personal health budget held by a 3rd party such as a brokerage organisation, who should agree with the individual how it is to be spent.

- 95.4 CCGs 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.

PG 96 Can an individual pay for additional services themselves in addition to their NHS continuing healthcare package?

- 96.1 DH published guidance⁴⁵ (referred to below as the 'Additional Private Care guidance') in March 2009 on NHS patients who wish to pay for additional private care, in addition to their NHS care package. Although it is primarily aimed at situations where NHS patients want to buy additional secondary and specialist care services that the NHS doesn't fund, it contains a set of principles applicable to all NHS services:

a) As affirmed by the NHS Constitution:

- the NHS provides a comprehensive service, available to all
- access to NHS services is based on clinical need, not an individual's ability to pay, and
- public funds for healthcare will be devoted solely to the benefit of the people that the NHS serves.

b) The fact that some NHS patients also receive private care separately should never be used as a means of downgrading or reducing the level of service that the NHS offers. NHS organisations should not withdraw any NHS care simply because a patient chooses to buy additional private care.

c) As overriding rules, it is essential that:

- the NHS should never subsidise private care with public money, which would breach core NHS principles, and
- patients should never be charged for their NHS care, or be allowed to pay towards an NHS service (except where specific legislation is in place to allow this) as this would contravene the founding principles and legislation of the NHS.

- 96.2 To avoid these risks, there should be as clear a separation as possible between private

⁴⁵ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_096428

and NHS care.

- 96.3 CCGs should seek to ensure that providers are aware of the above principles. Where a provider receives a request for additional privately-funded services from an individual who is funded by NHS continuing healthcare they should refer the matter to the CCG for consideration.
- 96.4 The following specific issues should be considered when dealing with additional private care issues in relation to NHS continuing healthcare:
- The NHS care package provided should be based on the individual's health and social care needs as identified in their care plan, developed from the multidisciplinary assessment in the NHS continuing healthcare eligibility process (including any changes to the care plan following review of the individual's needs).
 - The care plan should set out the services to be funded and/or provided by the NHS. It may also identify services to be provided by other organisations such as LAs but the NHS element of the care should always be clearly identified. Any care which would normally have provided in the course of good NHS practice should continue to be offered free of charge on the NHS.
 - Where an individual advises that they wish to purchase additional private care or services, CCGs should discuss the matter with the individual to seek to identify the reasons for this. If the individual advises that they have concerns that the existing care package is not sufficient or not appropriate to meet their needs, CCGs should offer to review the care package in order to identify whether a different package would more appropriately meet the individual's assessed needs.
 - CCGs should also be aware that individuals in receipt of NHS continuing healthcare continue to be eligible for all other services available to patients of their CCG. In developing or reviewing care packages, CCGs should consider whether other services commissioned or provided by the CCG would help meet the individual's needs.
 - The decision to purchase additional private care services should always be a voluntary one for the individual. Providers should not require the individual to purchase additional private care services as a condition of providing, or continuing to provide, NHS-funded services to them.
 - In the Additional Private Care guidance, 'separation' is defined as usually requiring the privately-funded care to take place in a different location and at a different time to the NHS-funded care. However, many individuals eligible for NHS continuing healthcare have limitations on their ability to leave their home due to their health needs. Moreover, the majority of the care they receive is often by its nature focused on supporting them within their own home and any additional private care may well also be focused on home-based support. Therefore, although the principle of separation still applies to NHS continuing healthcare, a different approach may be necessary. For example, where a person receives 24-hour NHS-funded support by way of a care home package it may not be possible for privately-funded care to be provided at a time that is separate to NHS-funded care. However, in such

circumstances, the private care should be delivered by different staff to those involved in delivering the NHS-funded care at the time it takes place and they should not be delivering treatment, care or support identified within the care plan as being part of the NHS-funded service.

- Although NHS-funded services must never be reduced or downgraded to take account of privately-funded care, the CCG and the organisations delivering NHS-funded care should, wherever clinically appropriate, liaise with those delivering privately-funded care in order to ensure safe and effective coordination between the services provided. Transfers of responsibility between privately-funded and NHS care should be carried out in a way which avoids putting individuals receiving services at any unnecessary risk. The CCG, the NHS-funded provider and the privately-funded provider should work collaboratively to put in place protocols to ensure effective risk management, timely sharing of information, continuity of care and coordination between NHS-funded and privately-funded care at all times. If different staff are involved in each element of care, these protocols should include arrangements for the safe and effective handover of the patient between those in charge of the NHS care, and those in charge of the privately-funded care.
- As when patients are transferred from one NHS organisation to another, it should always be clear which clinician/care provider staff and which organisation is responsible for the assessment of the patient, the delivery of any care and the delivery of any follow-up care.

PG 97 Example

- 97.1 Eileen lives in a care home as part of a care package funded via NHS continuing healthcare. She has significant difficulties in leaving the care home due to mobility needs. Her care plan identifies that she requires physiotherapy weekly which she receives from a physiotherapist employed by the CCG. Eileen considers that she wishes to purchase an additional session of physiotherapy weekly.
- 97.2 The CCG review her care plan and consider that one physiotherapy session a week is sufficient to meet her needs. Eileen decides that she would nevertheless like to purchase an additional session. She makes arrangements with a private physiotherapist for this purpose.
- 97.3 With Eileen's permission, the NHS and privately-funded physiotherapists liaise to ensure compatible approaches to the treatment that they will give, ensuring that the NHS treatment continues to be fully provided by the NHS physiotherapist. This is set out in a care plan agreed with Eileen.

PG 98 Example

- 98.1 John receives a support package funded via NHS continuing healthcare in his own home. The package is delivered by care workers from a private agency engaged by the NHS who visit to provide support every four hours. John considers that support should be provided more often and asks the CCG to increase the visits to every two hours. The CCG review John's support package and agree that more frequent support is needed during the evenings. They increase the frequency to every two hours each evening. However the CCG consider that four hourly visits are still appropriate during the daytime.
- 98.2 John still wishes to have additional support during the day and arranges with the same care provider to purchase additional visits every two hours. The CCG liaise with John and the care provider to develop mutual clarity on the additional support to be provided in the privately-funded visits as opposed to those provided in the NHS-funded visits. This is set out in a care plan agreed between the CCG, the care provider and John. The arrangements also include a single set of daily notes completed by the care provider's staff as a record of each visit so that, regardless of whether the most recent visit was NHS funded or privately funded, there is effective communication on John's current needs for the next staff who visit.

PG 99 Can an individual 'top-up' their care package to pay for higher-cost services or accommodation?

- 99.1 The funding provided by CCGs in NHS continuing healthcare packages should be sufficient to meet the needs identified in the care plan, based on the CCG's knowledge of the costs of services for the relevant needs in the locality where they are to be provided. It is also important that the models of support and the provider used are appropriate to the individual's needs and have the confidence of the person receiving the services.
- 99.2 Unless it is possible to separately identify and deliver the NHS-funded elements of the service, it will not usually be permissible for individuals to pay for higher-cost services and/or accommodation (as distinct from purchasing additional services). However, there may be circumstances where the CCG should consider the case for paying a higher-than-usual cost. For example, where an individual indicates a desire to pay for higher-cost accommodation or services, the relevant CCG should liaise with them to identify the reasons for the preference. Where the need is for identified clinical reasons (for example, an individual with challenging behaviour wishes to have a larger room because it is identified that the behaviour is linked to feeling confined, or an individual considers that they would benefit from a care provider with specialist skills rather than a generic care provider), consideration should be given as to whether it would be appropriate for the CCG to meet this.
- 99.3 In some circumstances individuals become eligible for NHS continuing healthcare when they are already resident in care home accommodation for which the fees are higher than the relevant CCG would usually meet for someone with their needs. This may be where the individual was previously funding their own care or where they were previously funded by an LA and a third party had 'topped up' the fees payable. 'Topping-

up' is legally permissible under legislation governing LA social care but is not permissible under NHS legislation. For this reason, there are some circumstances where a CCG may propose a move to different accommodation or a change in care provision.

- 99.4 In such situations, CCGs should consider whether there are reasons why they should meet the full cost of the care package, notwithstanding that it is at a higher rate, such as that the frailty, mental health needs or other relevant needs of the individual mean that a move to other accommodation could involve significant risk to their health and well being.
- 99.5 There may also be circumstances where an individual in an existing out of area placement becomes entitled to NHS continuing healthcare and where, although the care package is of a higher cost than the responsible CCG would usually meet for the person's needs, the cost is reasonable taking into account the market rates in the locality of the placement. CCGs should establish this by liaison with the CCG where the placement is located. In such circumstances CCGs should consider whether there are particular circumstances that make it reasonable to fund the higher rate. This could be because the location of the placement is close to family members who play an active role in the life of the individual or because the individual has resided in the placement for many years so that they have strong social links with the area and it would be significantly detrimental to the individual to move them.
- 99.6 CCGs should deal with the above situations with sensitivity and in close liaison with the individuals affected and, where appropriate, their families, the existing service provider and the local authority if they have up to this point been funding the care package. Where a CCG determines that circumstances do not justify them funding an existing higher cost placement or services that they have inherited responsibility for, any decisions on moves to other accommodation or changes in care provider should be taken in full consultation with the individual concerned and put in writing with reasons given. Advocacy support should be provided where this is appropriate.
- 99.7 Where an individual become entitled to NHS continuing healthcare and has an existing high-cost care package, CCGs should consider funding the full cost of the existing higher-cost package until a decision is made on whether to meet the higher cost package on an ongoing basis or to arrange an alternative placement.
- 99.8 Where separation of NHS and privately funded care arrangements is possible, the financial arrangements for the privately funded care is entirely a matter between the individual and the relevant provider and it should not form part of any service agreement between the CCG and the provider.
- 99.9 Where an individual wishes to dispute a decision not to pay for higher-cost accommodation, they should do this via the NHS complaints process. The letter from the CCG advising them of the decision should also include details of the complaints process and who to contact if the individual wishes to make a complaint.
- 99.10 The new accommodation and/or services should reflect the individual's assessed needs as identified in their care plan, including taking into account personal needs such as proximity to family members. Individuals should be provided with a reasonable choice of

providers. A transition care plan should be developed by the existing and new providers that identifies key needs and preferences, including how any specific needs and risks in the transition process should be addressed. The CCG should keep in regular liaison with the new provider and with the individual during the initial weeks of the new services to ensure that the transition has proceeded successfully and to ensure that any issues that have arisen are being appropriately addressed.

99.11 Further details are given in Personal Health Budgets: First Steps⁴⁶.

⁴⁶ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093842

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 etc) 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 continuing healthcare

A complete package of ongoing care arranged and funded solely by the NHS, where it has been assessed that the individual has a 'primary 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.

NHS-funded nursing care

Funding provided by the NHS to homes providing nursing to support the provision of nursing care by a registered nurse. Since 2007 NHS-funded nursing care has been based on a single band rate. 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.

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 and preferences.

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.

Representative

Any friend, unpaid carer or family member who is supporting the individual in the process as well as anyone acting in a more formal capacity (e.g. welfare deputy or power of attorney, or an organisation representing the individual).

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

1. 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.
2. 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.
3. 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 judgement 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 providethen 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.

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- 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 duty of clinical commissioning groups under section 3 of the National Health Service Act 2006 (as amended by the Health and Social Care Act 2012), is limited to providing the services identified, to the extent that they consider necessary to meet all reasonable requirements.
- 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

1. 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.
2. 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 NHS CB were contrary to the judgement 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.
3. Key relevant points from the Grogan judgement 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'.
4. 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.
5. 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 CCG 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), CCGs 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 CCG with sufficient information to establish an agreement with a care home for NHS-funded nursing services, and will trigger the CCG'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

1. CCGs and the NHS Commissioning Board (the Board) will assume responsibilities for NHS continuing healthcare from 1 April 2013.
2. The Board will assume commissioning responsibilities for some specified groups of people, for example for prisoners and military personnel. It therefore follows that the Board will have statutory responsibility for commissioning NHS continuing healthcare, where necessary, for those groups for whom it has commissioning responsibility. This will include case coordination, arranging completion of the Decision Support Tool, decision-making, arranging appropriate care packages, providing or ensuring the provision of case management support and monitoring and reviewing the needs of individuals. It will also include reviewing decisions with regards to eligibility where an individual wishes to challenge that decision.
3. Where an application is received for a review of a decision made by the Board, it must ensure that in organising a review of that decision, it makes appropriate arrangements to do so, so as to avoid any conflict of interest.

The purpose and scope of independent review panels

4. The standing rules require the NHS Commissioning Board (the Board) to maintain independent review panels (IRPs).
5. An IRP's key tasks are, at the request of the Board, to conduct a review of the following:
 - a) the procedure followed by a CCG in reaching a decision as to that person's eligibility for NHS continuing healthcare; or
 - b) the primary health need decision by a CCG.and to make a recommendation to the Board in the light of its findings on the above matters.
6. 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 Board should refer the case to the relevant CCG 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.
7. 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;

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- 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).
8. The IRP should apply the key principles for dispute resolution processes, as set out in paragraphs 145–158 of the National Framework.
 9. 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. The Board and CCGs 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.
 10. It is particularly important that, before an IRP is convened, all appropriate steps have been taken by the relevant CCG to resolve the case informally, in discussion with the NHS CB where necessary. The Board should have a named contact, who is the first port of call for queries from partner organisations for the relevant locality.
 11. If the case cannot be resolved by local resolution (or local resolution will cause undue delay), the individual (or their representative) may ask the NHS CB to arrange an IRP to review the case with regard to the matters listed in paragraph 5 above. Before doing so, the Board should ensure that none of the circumstances listed at paragraphs 6 and 7 of this annex apply. If any of them are applicable, the Board 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.
 12. The Board should designate individuals 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.
 13. Clear and timely communication is very important. The Board should develop and publish timescales for the hearing of IRP cases.
 14. The Board 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 Board 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 Board 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.
 15. 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 Board or CCG, using the process set out in paragraphs 139–144, if the individual's needs change or if the time for the next scheduled review of the individual has arrived. Please see Appendix F for guidance on responsibilities when a decision on NHS Continuing

Healthcare eligibility is awaited or is disputed.

Establishment and operation of the panels

16. IRP chairs should be selected by the NHS CB, 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.
17. 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 NHS staff, board members of NHS organisations, LA staff and LA elected members should not be considered but people who have formerly held such a position are eligible. The Board is advised to involve lay people in the selection process.
18. The appointment of representatives from CCGs 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.
19. The members of the IRP should meet to consider individual cases. A designated Board representative 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.
20. An individual may have a representative present to speak on his or her behalf if they so choose, or if they are unable to, 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.
21. 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.

22. 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.
23. An IRP may ask all parties to withdraw while it deliberates and agrees its recommendations. Where appropriate, an IRP may ask an NHS CB representative and/or the clinical adviser to be present to give advice. The NHS CB may also be represented in order to keep a record of deliberations.
24. In reaching a view on whether the Board or the CCG followed the correct process and whether it correctly applied the eligibility criteria, the range of recommendations made by the IRP for consideration by the Board and/ or the CCG could include:
 - a) that the case should be reconsidered by the Board or the CCG, 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.
25. 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 Board to all parties.
26. The recommendations of an IRP should be accepted by the Board in all but exceptional circumstances.
27. If the Board decides, in exceptional circumstances, not to accept an IRP recommendation in an individual case, it should explain this in writing to the individual, the CCG and the chair of the IRP, including its reasons for not accepting it.
28. In all cases, the NHS CB should communicate the outcome of the review, with its reasons, to the individual and the CCG.
29. A CCG should accept the recommendations of the IRP, as forwarded by the NHS CB, in all but exceptional circumstances. If a CCG 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 NHS CB, including its reasons. If an NHS CB or CCG does not accept the recommendations, and if the individual is dissatisfied with this, the matter should be pursued through the NHS complaints procedure.
30. The NHS CB or CCG, as appropriate, should ensure that the individual is informed in writing of their right to use the NHS complaints procedure in such circumstances.

Annex F: Guidance on responsibilities when a decision on NHS Continuing Healthcare eligibility is awaited or is disputed

1. This guidance sets out the approach to be taken by the Board, CCGs and local authorities (LAs) in three situations:
 - a) where there is a need for health or community care services to be provided to an individual during the period in which a decision on eligibility for NHS continuing healthcare is awaited, in a case that does not involve hospital discharge⁴⁷
 - b) where the Board or a CCG has unjustifiably taken longer than 28 days to reach a decision on eligibility for NHS continuing healthcare; or
 - c) where, as a result of an individual disputing an NHS continuing healthcare eligibility decision, the board or a CCG has revised its decision.
- a) Where care needs to be provided whilst a decision on NHS continuing healthcare is awaited, in a case that does not involve hospital discharge
2. A person only becomes eligible for NHS continuing healthcare once a decision on eligibility has been made by the Board or a CCG, informed by a completed Decision Support Tool or Fast Track Pathway Tool. Prior to that decision being made, any existing arrangements for the provision and funding of care should continue, unless there is an urgent need for adjustment.
3. If, at the time of referral for an NHS continuing healthcare assessment, the individual is already receiving an ongoing care package funded by the Board or a CCG, or an LA, or both, those arrangements should continue until the Board or CCG makes its decision on eligibility for NHS continuing healthcare, subject to any urgent adjustments needed to meet the changed needs of the individual. In considering such adjustments, LAs and CCGs/the Board should have regard to the limitations of their statutory powers.
4. Some health needs fall within the powers of both CCGs/the Board and LAs to meet. However where:
 - i) an LA is providing services during the period in which an NHC continuing healthcare eligibility decision is awaited; and
 - ii) it is identified that the individual has some health needs that are **not** within the power of an LA to meet (regardless of the eventual outcome of the NHS continuing healthcare eligibility decision); and
 - iii) those health needs have to be met before the decision on eligibility is made;

the Board CCG should consider its responsibilities under the NHS 2006 Act to provide such health services to such extent as it considers necessary to meet all reasonable requirements. The Board or CCG should therefore consider whether the individual's health needs are such that it would be appropriate to make services available to help meet them

⁴⁷ The position where an individual is being discharged from hospital is set out in paragraphs 62 - 67 of this Framework

in advance of the NHS continuing healthcare eligibility decision.

5. Where an individual is not already in receipt of an ongoing care package from the LA or CCG/ Board (or both), they may have urgent health or social care needs which need to be met during the period in which the NHS continuing healthcare eligibility decision is awaited, for example because previous private arrangements are no longer sustainable or there were not previously any care needs requiring support. Where there are urgent healthcare needs to be met, these should be assessed by the relevant healthcare professional.
6. Where the individual appears to be in need of community care services, the LA should assess the individual's eligibility for these under section 47 of the NHS and Community Care Act 1990 (the 1990 Act), including consideration of whether there is a need to provide services urgently in advance of such assessment, using their powers under section 47(5) of the 1990 Act.
7. If, in carrying out an assessment, the LA identifies that there may be a need for health services under the 2006 Act, the LA should invite the CCG/the Board to participate in the assessment (see section 47(3) of the 1990 Act). The Board or the CCG should consider and meet its responsibilities under the NHS Act 2006 pending the NHS continuing healthcare eligibility decision, as explained above. The LA and CCG/ the Board should jointly agree actions to be taken in the light of their statutory responsibilities until the outcome of the NHS continuing healthcare decision-making process is known. No individual should be left without appropriate support because statutory bodies are unable to agree on respective responsibilities.

b) Where the Board or a CCG has unjustifiably taken longer than 28 days to reach a decision on eligibility for NHS continuing healthcare

8. Decision-making on eligibility for NHS continuing healthcare should, in most cases, take no longer than 28 days from receipt of a completed Checklist (or, where no Checklist is used, other notification of potential eligibility for NHS continuing healthcare). See paragraph 95 of this Framework.
9. When
 - i) the Board or a CCG makes a decision that a person is eligible for NHS continuing healthcare; and
 - ii) it has taken more than 28 days to reach this decision; and
 - iii) an LA or the individual has funded services whilst awaiting the decision;

the Board or the CCG should, having regard to the approaches set out in paragraphs 11 to 13 below, refund directly to the individual or the LA, the costs of the services from day 29 of the period that starts on the date of receipt of a completed Checklist (or where no Checklist is used, other notification of potential eligibility for NHS continuing healthcare), and ends on the date that the decision was made. This period is referred to below as the "period of unreasonable delay". The refund should be made unless the Board or the CCG can demonstrate that the delay is reasonable as it is due to circumstances beyond the Board's or the CCG's control, which could include:

- i) evidence (such as assessments or care records) essential for reaching a decision on eligibility have been requested from a third party and there has been delay in receiving

- these records from them;
- ii) the individual or their representatives have been asked for essential information or evidence or for participation in the process and there has been a delay in receiving a response from them;
 - iii) there has been a delay in convening a multidisciplinary team due to the lack of availability of a non-CCG practitioner whose attendance is key to determining eligibility and it is not practicable for them to give their input by alternative means such as written communication or by telephone.
10. In all of the above and other circumstances, the Board and CCGs should make all reasonable efforts to ensure the required information or participation is made available within 28 days. This should include developing protocols with services likely to be regularly involved in NHS continuing healthcare eligibility processes that reflect the need for information or participation within 28 days. Where the Board or CCG commissions the service from which information or participation is regularly required, it may be appropriate to consider placing such expectations within the specification for the relevant service.
11. The Board, CCGs and LAs should be aware of the requirements of the Standing Rules Regulations and Directions to LAs for the Board or a CCG to consult the relevant LA, wherever reasonably practicable, before making a decision on NHS continuing healthcare eligibility and for the LA, wherever reasonably practicable, to provide advice and assistance to the Board or to the relevant CCG.
12. Where unreasonable delay has occurred and it is an LA that has funded services during the interim period, the Board or the CCG should refund the LA the costs of the care package that it has incurred during the period of unreasonable delay. The Board or CCG can use its powers under section 256 of the 2006 Act to make such payments. The amount to be refunded to the LA should be based on the gross cost of the services provided. Where an individual has been required to make financial contributions to the LA as a result of an assessment of their resources under the 1990 Act, the above approach should be adopted rather than the Board or the CCG refunding such contributions directly to the individual as the refund of contributions is a matter between the LA and the individual. Where the Board or a CCG makes a gross cost refund, the LA should refund any financial contributions made to it by the individual in the light of the fact that it has been refunded on a gross basis, including interest.
13. Where the Board or a CCG has unreasonably delayed reaching its decision on eligibility for NHS continuing healthcare, and the individual has arranged and paid for services directly during the interim period, the Board or the CCG should make an ex-gratia payment in respect of the period of unreasonable delay.
14. Such payments would need to be made in accordance with the guidance for ex-gratia payments set out in Managing Public Money⁴⁸. This sets out (in paragraph 4.12.4) that, where public services organisations have caused injustice or hardship, they should provide remedies that, as far as reasonably possible, restore the wronged party to the position that they would have been in had matters been carried out correctly. This guidance (in Annex 4.14) sets out other issues to be considered and the Board and CCGs should take these into account in reaching their decision.

⁴⁸ http://www.hm-treasury.gov.uk/psr_mpm_index.htm

c) Where, as a result of an individual disputing an NHS continuing healthcare eligibility decision, the Board or a CCG has revised its decision

15. When the Board or a CCG has made a decision on NHS continuing healthcare eligibility, that decision remains in effect until the Board or the CCG revises the decision. This Framework sets out that IRPs make recommendations but that these recommendations should be accepted by the Board or a CCG in all but exceptional circumstances. Where the Board or a CCG accepts an IRP recommendation on NHS continuing healthcare eligibility, it is in effect revising its previous decision in the light of that recommendation.

16. Where:

i) an LA has provided community care services to an individual in circumstances where the Board or a CCG has decided that the individual is not eligible for NHS continuing healthcare, and

ii) the individual disputes the decision that they are not eligible for NHS continuing healthcare and the Board's or the CCG's decision is later revised (including where the revised decision is as a result of an IRP recommendation),

the Board or the CCG should refund the LA the costs of the care package. This should be based on the gross care package costs that the LA has incurred from the date of the decision that the individual was not eligible for NHS continuing healthcare (or earlier, if that decision was unreasonably delayed – see the previous section) until the date that the revised decision comes into effect. The Board or a CCG can use its powers under section 256 of the 2006 Act to make such payments. Where the LA has collected an assessed charge from the individual, the refund from the Board or the CCG should include interest on that amount so that this can be reimbursed to the individual (see paragraph 16 below)

17. Where the Board or a CCG makes such a refund, the LA should refund any financial contributions made to it by the individual (with interest) in the light of the fact that it has been refunded on this basis.

18. Where:

i) no LA has provided community care services to an individual in circumstances where the Board or a CCG has decided that the individual is not eligible for NHS continuing healthcare, and

ii) the individual has arranged and paid for such services him or herself; and

iii) the individual disputes the decision that they are not eligible for NHS continuing healthcare and the Board's or a CCG's decision is later revised (including where the revised decision is as a result of an IRP recommendation),

the Board or the CCG should make an ex-gratia payment directly to the individual. When the Board or a CCG has revised its decision, whether as a result of an IRP process or not, this is a recognition that the original decision, or the process leading up to the decision, was incorrect. An ex-gratia payment would be to remedy any injustice or hardship suffered by the individual as a result of the incorrect decision. The Board or a CCG should take into account the Managing Public Money guidance as explained above.

Disputes

19. It is important that the Board/ CCGs and LAs have clear jointly agreed local processes for resolving any disputes that arise between them on the issues covered in this guidance. The Standing Rules Regulations and Directions to LAs require the Board or CCGs and LAs to have an agreed local process for resolving disputes between them on issues relating to eligibility for NHS continuing healthcare and for the NHS elements of joint packages. The Board, CCGs and LAs could extend the remit of their local disputes process to include disputes over refunds. Whatever disputes process is selected, it is important that it should not simply be a forum for further discussion but includes an identified mechanism for final resolution, such as referring the case to another CCG and LA and agreeing to accept their recommendation.
20. Where an individual disputes the Board's or a CCG's decision on whether to provide redress to them, or disputes the amount of redress payable, this should be considered by the Board or CCG through the NHS complaints process.

Annex G: Local NHS Continuing Healthcare Protocols

The following provides a best practice guide for what to include when drawing up and updating local protocols and procedures regarding NHS continuing healthcare.

Referrals, Assessments and Recommendations

- A statement about the principles underlying the process to ensure that it is 'person-centred', equitable, culturally sensitive, robust, transparent and lawful. This includes ensuring equitable access to assessment for NHS continuing healthcare based on need (not on client group, current funding arrangements, etc.) and using the Checklist as a basis for identifying those who require full assessment to inform completion of the DST.
- Arrangements for ensuring that the patient/client and their family are kept informed and involved at every stage, including being informed of their right to appeal if they are not satisfied with the eligibility decision regarding NHS continuing healthcare.
- Arrangements (and possibly local forms) for obtaining consent to the different stages of the process where the individual has capacity. Also arrangements for dealing with situations where an individual with capacity refuses consent to assessment for NHS continuing healthcare.
- Local arrangements for dealing with situations where the individual appears to lack capacity, in order to ensure compliance with the Mental Capacity Act 2005 and the associated Code of Practice, including how to access the IMCA service where necessary.
- Local arrangements regarding how individuals can access advocacy, advice and information.
- An explanation of who can complete the Checklist (and what training they need beforehand), bearing in mind that the aim is to allow a variety of people, in a variety of settings, to refer individuals for a full assessment for NHS continuing healthcare. The Checklist clarifies (paragraph 3) that it is for each organisation to decide for itself who are the most appropriate staff to participate in the completion of a Checklist.
- Arrangements to ensure that individuals/representatives are informed in writing about the outcome of the Checklist and given a copy, whether or not they cross the threshold for full consideration of NHS continuing healthcare eligibility.
- How and in what situations Fast Track arrangements are to operate, including a statement that the Fast Track Pathway Tool is to be completed by an 'appropriate clinician' as defined in the Standing Rules Regulations [DN – this is at Reg 23(12)] and is to be acted on by the Board or the CCG without delay. It is important to ensure that decision-making around NHS continuing healthcare does not in any way compromise the provision of good end of life care.
- Arrangements for the timely provision of care/support in fast-track cases, including provision of equipment where necessary.

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- The referral process being clear where cases requiring full consideration of eligibility using the DST are to be directed (this may well differ depending on whether the individual concerned is currently in hospital, in a care home or in the community). Clarity on the method of delivery of paperwork is needed to minimise delay but ensure confidentiality.
- An agreement that the key agencies will make staff available to participate in the assessment and decision-making processes, including making staff available to sit on Independent Review Panels.
- Any specific local arrangements around appointing coordinators, identifying members of the MDT and convening MDT meetings. These arrangements need to ensure as far as possible that both NHS and social care colleagues are involved in the assessment process.
- Arrangements for dealing with people subject to section 117 of the Mental Health Act 1983, with reference to paragraphs 188 - 122.
- Clarity on how the NHS continuing healthcare process fits with hospital discharge arrangements, with reference to paragraphs 62 – 67 of the National Framework.
- Arrangements for care/support and funding (including ‘without prejudice’ funding) whilst the decision-making process is carried out, noting that if someone is being discharged from hospital then the CCG retains funding responsibility whilst the DST is being completed and the eligibility decision is being made.
- How transfers of care are to be handled, including effective risk management.
- Arrangements for reviewing:
 - care packages/placements where an individual is in receipt of NHS continuing healthcare.
 - Joint packages of care
 - Individuals in receipt of NHS-funded nursing care
- Timeframes for each stage of the process.

N.B. visual representation of the process in flow-charts is often very helpful.

Decision-making

Arrangements must be in place to ensure that (so far as is reasonably practicable) the LA’s views regarding needs and eligibility are obtained before decisions are made regarding eligibility for NHS continuing healthcare. There should be robust arrangements for joint decision-making between the CCG and LA. This may or may not include a panel arrangement, but care should be taken to ensure that panels are not used unnecessarily (see PG39).

- Terms of reference for panel (where these exist)– purpose of panel, which cases are to be referred, client groups covered, limitations of decision-making powers, bearing in mind that the National Framework states that *‘only in exceptional circumstances, and for clearly articulated reasons, should the multidisciplinary team’s recommendation not be followed* (see paragraph 91).

- Arrangements and process for obtaining the LA's views where a panel process is not in place.
- Membership and chairing arrangements (some have independent chairs).
- Arrangements for panel members to have sight of case documentation in advance.
- Whether/how the individual and/or their representative is to be involved in the panel arrangements.
- What counts as a quorum.
- Frequency of meetings.
- Access to specialist input/advice.
- Paperwork expected (including DST) to inform discussion.
- Arrangements for recording main points of panel discussion and decisions.
- Clarity on decision-making, voting arrangements (if any), etc. On some panels LA members have an equal say (which is good practice); others limit LA involvement to advice from a social care perspective. There is a need to be clear that financial considerations do not influence the decision regarding eligibility for NHS continuing healthcare.
- Procedure for dealing with disagreement over eligibility within the panel meetings.
- Local resolution process where an individual or their representative is unhappy with the eligibility decision.

Dispute Avoidance and Resolution between Agencies

Good communication, effective joint working and mutual respect are key to avoiding unnecessary disputes. Any local protocols should consider:

- Clarity on what counts as a disagreement and what counts as a formal dispute – some protocols include disagreements/disputes at Checklist and DST stage as well as at panel decision-making stage.
- Different levels of dispute resolution – the aim is usually to resolve disputes at practitioner level but most procedures have the option of escalating the dispute through appropriate levels to senior management level where necessary. Some dispute resolution processes include referring the case to a second panel to check the original decision; in some cases there are agreements to refer to a panel in another area. It is important that dispute resolution processes have a clear end, final resolution point.
- What types of dispute are covered – protocols should deal with disputes over NHS continuing healthcare eligibility, joint funding arrangements and refunds.

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- What paperwork/information is needed at each stage.
- Timescales at each stage of the process.
- Arrangements to ensure individuals get the care/support they need whilst disputes are being resolved, bearing in mind the principle of 'no unilateral withdrawal of funding'.
- Clarity on what happens over interim or 'without prejudice' funding – including over any backdating arrangements for reimbursing costs and how charging the service user will be handled in a variety of possible situations, having regard to the approaches set out in Annex F above.