

# **NHS Continuing Healthcare Practice Guidance**



**March 2010**

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Policy	Estates
HR/Workforce	Commissioning
Management	IM&T
Planning/Performance	Finance
Clinical	<b>Social Care/Partnership Working</b>

<b>Document purpose</b>	Best Practice Guidance
<b>Gateway reference</b>	<b>13202</b>
<b>Title</b>	NHS Continuing Healthcare Practice Guide
<b>Author</b>	Older People and Dementia, NHS CHC working group
<b>Publication date</b>	01 March 2010
<b>Target audience</b>	PCT CEs, SHA CEs, Care Trust CEs, Directors of Nursing, Directors of Audit SSs, Directors of Commissioning
<b>Circulation list</b>	This guidance is intended to support practitioners and others with responsibi
<b>Description</b>	This guidance is intended to support practitioners and others with responsibilities for NHS continuing healthcare in the implementation of the revised national framework of July 2009 and in the use of associated tools
<b>Cross ref</b>	National Framework for NHS Continuing Healthcare and NHS-funded Nursing care July 2009 (revised)
<b>Superseded docs</b>	
<b>Action required</b>	Implementation
<b>Timing</b>	<b>From April 1</b>
<b>Contact details</b>	SCPI-SR-CORRES@dh.gsi.gov.uk Older People and Dementia Branch Room 8E13 Quarry Hill Leeds LS2 7UE
<b>For recipient's use</b>	

# Contents

1.	Introduction	4
2.	Key Principles	5
3.	Mental Capacity and NHS Continuing Healthcare	19
4.	Key Concepts	22
5.	The Fast Track Pathway Tool for NHS Continuing Healthcare	28
6.	Screening for NHS Continuing Healthcare – the Use of the Checklist Tool	34
7.	Hospital Discharge Policy and Interim Processes	41
8.	Multidisciplinary Assessment, Completion of the DST and Making Recommendations	44
9.	Eligibility and Panel Processes	54
10.	Disputes	56
11.	Care Planning, Commissioning and Personalisation	59
	Appendix: Local NHS Continuing Healthcare Protocols	83

# 1. Introduction

1.1 This Practice Guidance is intended to support practitioners and others with responsibilities for NHS continuing healthcare in the implementation of the *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care: July 2009 (revised)* (referred to in this guidance as 'the Framework') and in the use of the associated tools. An explanation of NHS continuing healthcare is to be found at paragraphs 8 and 9 of the Framework. This Practice Guidance provides a practical explanation of how the Framework should operate on a day-to-day basis and cites examples of good practice. It is not a substitute for the Framework and associated tools; indeed it is essential to read and understand them and the underlying principles before using this Practice Guidance. The key relevant documents are:

- a) *The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care: July 2009 (revised)*<sup>1</sup>
- b) *NHS Continuing Healthcare Checklist: July 2009*
- c) *Decision Support Tool for NHS Continuing Healthcare: July 2009*
- d) *Fast Track Pathway Tool for NHS Continuing Healthcare: July 2009*<sup>2</sup>
- e) *The NHS Continuing Healthcare (Responsibilities) Directions 2009* (referred to below as 'the Responsibilities Directions')
- f) *The Delayed Discharges (Continuing Care) Directions 2009*
- g) *The National Health Service (Nursing Care in Residential Accommodation) (England) Directions 2007, as amended by the National Health Service (Nursing Care in Residential Accommodation) (Amendment) (England) Directions 2009*.<sup>3</sup>

1.2 There has been a 'Frequently Asked Questions' (FAQ) section on the Department of Health (DH) website on this subject for some time and this will be updated in the light of the revised Framework and periodically updated.<sup>4</sup>

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<sup>1</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_103162](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_103162)

<sup>2</sup> The three tools are available at: [http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Continuingcare/DH\\_073912](http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Continuingcare/DH_073912)

<sup>3</sup> The Responsibilities Directions are available at: [http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Continuingcare/DH\\_079288](http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Continuingcare/DH_079288)

<sup>4</sup> [http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Continuingcare/DH\\_079276](http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Continuingcare/DH_079276)

## 2. Key Principles

### 2.1 What is the role of the PCT in relation to NHS continuing healthcare?

Primary Care Trusts (PCTs) have the lead responsibility for NHS continuing healthcare in their locality (but there are also specific requirements for local authorities (LAs) to cooperate and work in partnership with their local PCT in a number of key areas). In addition PCTs 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.

Paragraph 166 of the Framework sets out best practice governance responsibilities of PCTs. These are expanded on below.

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

This may be achieved, for example, through PCTs:

- > 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.

#### 2.1.2 ***Promoting awareness of NHS continuing healthcare***

This may be achieved, for example, through:

- > ensuring that the public information leaflet is available in appropriate formats and languages at key locations
- > providing information on PCT and LA websites

- > providing awareness raising sessions for staff
- > using existing networks, for example LINKs (Local Involvement Networks), to promote better understanding of NHS continuing healthcare
- > working with independent and/or voluntary organisations to promote awareness.

#### **2.1.3 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.

#### **2.1.4 Ensuring that quality standards are met and sustained**

This could, for example, include:

- > agreement of quality standards across key agencies
- > use of auditing tools to check process and quality at different stages
- > learning from complaints/compliments.

#### **2.1.5 Providing training and development opportunities for practitioners**

The PCT'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 PCT has to carry out or fund all the training itself. The PCT'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/case managers and others in NHS continuing healthcare roles across organisations
- > ensuring training is available to 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.

### **2.1.6 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.

### **2.1.7 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 PCT 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 PCT lead for liaison with providers.

## 2.2 What is the role of the LA in NHS continuing healthcare?

The Responsibilities Directions require PCTs 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 2010<sup>5</sup> should be used to identify the relevant social services authority.)

The Responsibilities Directions also require the social services authority to provide advice and assistance to the PCT 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.

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 PCT in carrying out its responsibilities.

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 PCT has received a referral for NHS continuing healthcare
- > working jointly with PCTs 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 PCTs retain formal commissioning and care planning responsibility for those eligible for NHS continuing healthcare).

The Responsibilities Directions also include a separate duty for LAs to make nominations to Strategic Health Authorities (SHAs) of potential members of Independent Review Panels (IRPs) whenever requested by the SHA and, where appointed, to make their nominees available to participate in IRPs as far as reasonably practicable.

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<sup>5</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_113627](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113627)

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

The Framework makes it clear that 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.

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?'*

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

- > ensure that the person concerned is fully and directly involved in the assessment and the decision-making process
- > 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
- > address communication and language needs
- > obtain consent to assessment and sharing of records (where the individual has mental capacity to give this)
- > deal openly with issues of risk
- > keep the individual informed.

#### 2.3.1 **Ensuring that the person concerned 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 2.5 below).

**2.3.2 *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.

**2.3.3 *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 simplified language or pictures may be helpful. 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. PCTs should consider the most likely communication needs to arise in the course of assessing for 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.

#### **Practice Example**

Clare has advanced MS and is severely physically disabled. She can't move or communicate verbally. Her husband provides much of her personal care at home, which he is willing to continue to do. However, during a period in hospital for a chest infection concerns were raised about some bruising she had and consideration was being given to implementing safeguarding procedures. The hospital consultant was uncertain whether Clare had capacity to decide whether she should go home. However, the speech and language therapist was able to communicate with Clare using pictures and words and confirmed that she could communicate (albeit slowly) using eye and head movements. It was ascertained that there was no reason to doubt she had capacity to make informed decisions regarding her care. Clare was able to clearly indicate that the bruising had happened accidentally and that it was definitely her wish to return home and for her husband to continue to provide her care.

#### **2.3.4 Obtaining consent to assessment and sharing of records**

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

The NHS Code of Confidentiality<sup>6</sup> 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 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'*

<sup>6</sup> [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4069254.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4069254.pdf)

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...'*

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.

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.

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. 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 full 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.

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 and the PCT to reach an informed decision in eligibility should be explained to the individual. However, they should not 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

### 2.3.5 ***Dealing openly with issues of risk***

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.

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 making* sets out wider best practice on this issue.<sup>7</sup> 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.'*

<sup>7</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_074773](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074773)

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.

The guidance also includes best practice approaches to decision making on risk issues, including a supported decision tool.

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

#### **2.3.6 Keeping the individual informed**

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.

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

Paragraph 38 of the Framework explains the formal position in relation to refusal of consent, and should be read in conjunction with the additional guidance set out below. *The Reference Guide to Examination or Treatment*<sup>8</sup>, although focused on examination and treatment issues, also contains principles that should also be taken into account.

- 2.4.1 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).
- 2.4.2 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 PCT can do to personalise care/support and give them as much control as possible. Fuller details of approaches on this are in section 11.
- 2.4.3 The fact that an individual refuses to be assessed for continuing healthcare eligibility does not, in itself, mean that the LA has an additional responsibility to meet their needs over and above what they would be responsible for if consent had been given. If there are significant concerns that the individual does have ongoing needs and the level of support required to meet them could be affected by their decision not to consent then the PCT and LA should jointly agree the way forward at a senior management level, taking into account their powers and duties and obtaining legal advice where appropriate. If an LA decides that the absence of consent means that services can no longer be provided they should give reasonable notice and clear

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<sup>8</sup> [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_103653.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_103653.pdf)

reasons to the person and give them the opportunity to request a review of the decision or to take it through the complaints process.

- 2.4.4 Although refusal of consent only occurs in a minority of cases, PCTs 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.

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

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 PCTs 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.

The Framework says (paragraph 44) that '*PCTs should ensure that individuals are made aware of local advocacy and other services that may be able to offer advice and support, and should also consider whether any strategic action is needed to ensure that adequate advocacy services are available to support those who are eligible and potentially eligible for NHS continuing healthcare.*' The latter could be achieved by the PCT having protocols with local advocacy services about how they will support individuals around NHS continuing healthcare and 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.

For advocacy in relation to IRPs, the Framework states that SHAs and PCTs should ensure that there are agreed protocols as to how the provision of advocates will operate and the circumstances in which they are to be made available. SHAs and PCTs could link such protocols with the strategic development of advocacy services discussed above.

See 3.6 for details regarding the role of the Independent Mental Capacity Advocate (IMCA) where individuals lack mental capacity in relation to specific decisions.

## **2.6 Do individuals need to have legal representation during the NHS continuing healthcare eligibility process?**

No, although individuals are free to choose whether they wish to have an advocate present, and to choose who this advocate is. The Framework (supported by the Responsibilities Directions) 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.

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 are raised by advocates (such as legal questions) they should, if appropriate, be asked to raise these separately with the PCT outside the MDT meeting.

## **2.7 What information is available to give to members of the public about NHS continuing healthcare?**

A public information leaflet, entitled *NHS continuing healthcare and NHS-funded nursing care* is available.<sup>9</sup> PCTs should make these available to members of the public, for example through local NHS websites, hard copies on hospital wards, and through primary care outlets 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.

Some areas have produced their own local versions of the public information leaflet which include details of the local processes for assessment and for determining eligibility, as well as information on what to do where individuals have concerns or disagree with decisions made.

The PCT has overall responsibility for communicating with the public regarding NHS continuing healthcare and should consider the need to make information available in alternative formats and languages to ensure that it is accessible to all who may need it.

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<sup>9</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_106230](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_106230)

**2.8 Why is it important to complete the equality monitoring forms with the tools?**

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 PCTs 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 PCT to enable the PCT to monitor whether the Framework is being applied equitably in its area. If a PCT identifies any issues for particular groups or communities it should take steps to address these.

**2.9 Can the national tools be changed?**

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

## 3. Mental Capacity and NHS Continuing Healthcare

3.1 Paragraphs 39 to 42 of the Framework address the need to apply the principles of the Mental Capacity Act 2005 when dealing with issues of capacity and consent in relation to NHS continuing healthcare. The following paragraphs give further guidance on how the principles of the Act should be applied.

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

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

3.3 Carrying out an assessment for consideration for 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 the PCT, in accordance with the expectations of the Framework, has appointed a coordinator for the continuing healthcare eligibility process, this person will usually have the responsibility. Where a Checklist or Fast Track Pathway Tool is being completed, responsibility will usually lie with the person completing the Tool. PCTs and LAs should ensure that all staff involved in 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.

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 ask to see a copy of the certified Deputyship Order or registered and certified 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).

- 3.4 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).

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.

Those making best interests decisions should be aware that the Framework advises that everyone who is potentially eligible for NHS continuing healthcare should have the opportunity to be considered for eligibility.

3.5 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.

### 3.6 **When is it appropriate to involve an Independent Mental Capacity Advocate (IMCA)?**

The Framework reminds NHS bodies and LAs that they have a duty under the Mental Capacity Act 2005 to instruct and consult an IMCA if an individual lacks capacity in relation to particular decisions in their life and has no family or friends that are available (or appropriate) for consultation on their behalf. Where there is no one else appropriate to consult with (other than paid workers) an IMCA should be appointed where the decision relates to serious medical treatment (as defined in the Mental Capacity Act), hospital admission for longer than 28 days, a permanent change in the person's current residence or a temporary one that will last more than eight weeks.

In the context of an assessment for NHS continuing healthcare eligibility an IMCA should be appointed as soon as a preliminary view is taken that the outcome of the assessment is likely to result in the statutory criteria for an IMCA being met. In most cases this will be because the preliminary view is that a permanent change in residence is likely (e.g. a move to a care home) – irrespective of who subsequently accepts funding responsibility. Whilst an IMCA can be appointed by either a decision-maker in an LA or the NHS, where full consideration for eligibility for NHS continuing healthcare is being undertaken it would be best practice for the PCT to appoint the IMCA. Where an IMCA has been appointed a permanent decision should not be made on the issue in question until the IMCA report has been submitted and considered by the decision-maker.

Referrals for an IMCA should be made in accordance with local processes. It is important that decision-makers remember that separate referrals need to be made for different decisions, e.g. someone facing a potential accommodation move and a serious medical treatment decision will require separate referrals by the two relevant decision-makers.

## 4. Key Concepts

### 4.1 What is a primary health need?

'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 its 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 3 (1) (d)]. The Framework (paragraph 25) 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.'*

The term 'primary health need' does not appear in primary legislation, although it is referred to in the Responsibilities Directions 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'*

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'.

4.2 In simple terms (not a legal definition) 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.

4.3 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.

- 4.4 Each individual case has to be considered on its own merits in accordance with the principles outlined in the Framework. The Framework cautions against drawing generalisations about eligibility for NHS continuing healthcare from general information about cases reported from court decisions or by the Ombudsman.
- 4.5 The Framework states that 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 of the Framework). It further states 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. The totality of the overall needs and the effects of the interaction of needs should be carefully considered.'*
- 4.6 Although the Framework offers definitions of these four characteristics, it may be helpful for MDTs to think about them in terms of the sorts of questions that each characteristic generates. By the MDT answering these questions they develop a good understanding of the characteristic in question.
- 4.7 **'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?

- 4.8 **'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?

4.9 **'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?

4.10 **'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?

#### **4.11 What is the difference between a healthcare need and a social care need?**

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).

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.

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.

PCTs 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.

#### **4.12 What is the relationship between NHS-funded nursing care and NHS continuing healthcare?**

Eligibility for NHS continuing healthcare should be considered and a decision made and recorded (either at the Checklist or DST stage) before consideration is given to the provision of NHS-funded nursing care.

#### **4.13 What is the relationship between NHS continuing healthcare and section 117 after-care under the Mental Health Act?**

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. Whether section 117 services are being funded by a PCT or a LA there should be no charge to the individual.

Guidance<sup>10</sup> states that LAs and PCTs 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 PCTs 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 PCT fully funding a section 117 package this does not constitute NHS continuing healthcare.

It is preferable for a PCT 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.

#### **4.14 What can key agencies do to improve partnership working in relation to NHS continuing healthcare?**

NHS continuing healthcare can only be delivered successfully through a partnership approach at both organisational and practitioner levels between the PCT, LA, 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. The appendix contains a checklist of 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:

- > PCTs 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
- > PCTs and LAs developing similar approaches to risk and enablement
- > PCTs, 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

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<sup>10</sup> LAC 2000(3) which can be found at [http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/LocalAuthorityCirculars/AllLocalAuthority/DH\\_4003625](http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/LocalAuthorityCirculars/AllLocalAuthority/DH_4003625)

- > 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.

**Examples of good partnership working include:**

- ✓ the LA and PCT having unified commissioning/contracting arrangements, with one organisation commissioning and/or contracting on behalf of both
- ✓ joint brokerage arrangements between the LA and PCT
- ✓ joint delivery of training
- ✓ joint arrangements for hospital discharge
- ✓ coordinators funded by the PCT 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 PCT staff to undertake NHS continuing healthcare assessments
- ✓ Arrangements to jointly review those receiving NHS continuing healthcare
- ✓ PCT 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 a continuing healthcare team
- ✓ Joint funding of advocacy services by PCTs and LAs

## 5. The Fast Track Pathway Tool for NHS Continuing Healthcare

### 5.1 What is the Fast Track Pathway Tool?

The Fast Track Pathway Tool is used to gain immediate access to NHS continuing healthcare funding where an individual needs an urgent package of care/support. This Tool bypasses the Checklist and DST and should only be used for individuals who have a primary health need through a rapidly deteriorating condition that may be entering a terminal phase, and have an increased level of dependency.

### 5.2 Who can complete the Fast Track Pathway Tool?

The Framework makes it clear that the Fast Track Pathway 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.*

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. 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 a Fast Track Pathway Tool be completed. Alternatively they could approach the relevant PCT and make the request.

**5.3 Is the use of the Fast Track Pathway Tool compulsory?**

Yes, the Responsibilities Directions state that the Fast Track Pathway Tool must be used when an individual requires an urgent package of continuing healthcare due to a rapidly deteriorating condition that may be entering a terminal phase. No variations on the Tool should be used. It is only where the Fast Track Pathway Tool is used that a PCT is required by the Responsibilities Directions to decide immediately that the person is eligible for NHS continuing healthcare.

**5.4 What is the relationship between the Fast Track Pathway Tool and the Checklist/Decision Support Tool?**

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.

**5.5 Do individuals need to consent to a Fast Track Pathway Tool being completed?**

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.

**5.6 What happens if the individual is unable to provide consent to a Fast Track Pathway Tool being completed?**

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. Section 3 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.

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

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.

### 5.8 What evidence is required when completing the Fast Track Pathway Tool?

The intention of the Fast Track Pathway Tool 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 sufficient evidence to establish eligibility.

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 PCT 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 Strategy<sup>11</sup>. 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 Framework*<sup>12</sup>, *Preferred Priorities for Care*<sup>13</sup>. In doing this, it is important to advise the person on the range of options available (e.g. home support, hospice, etc.). PCTs 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. PCTs 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 continuing healthcare eligibility and so should facilitate availability of the required information. Continuing healthcare assessors should work in partnership with local end of life care leads in each individual case to ensure there is a single pathway and care plan agreed with the individual. This should be regularly reviewed and amended to reflect changing needs.

<sup>11</sup> [http://www.endoflifecare.nhs.uk/eolc/files/DH-EoLC\\_Strategy\\_promoting\\_high\\_quality\\_Jul2008.pdf](http://www.endoflifecare.nhs.uk/eolc/files/DH-EoLC_Strategy_promoting_high_quality_Jul2008.pdf)

<sup>12</sup> <http://www.goldstandardsframework.nhs.uk/>

<sup>13</sup> <http://www.endoflifecare.nhs.uk/eolc/CS310.htm>

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, PCTs 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.

It is also important for the PCT 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).

#### **5.9 Can a PCT refuse to accept a completed Fast Track Pathway Tool?**

No, the Responsibilities Directions make it clear that a PCT 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.

The purpose of the Tool is to ensure that the individual receives the support they need as quickly as possible without the need for a full consideration through the NHS continuing healthcare process. A PCT should not require any additional evidence to support eligibility although, as explained above, additional information to help identify the support package required can be helpful.

PCTs should not decline acceptance of a completed Fast Track Pathway Tool when the Tool states that the criteria in 5.1 are met. The individual should not experience a delay in receiving appropriate care just because a PCT 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.

However, exceptionally, there may be circumstances where PCTs 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 PCT 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.

On receipt of the Fast Track documentation the PCT should arrange for the care package to be commissioned without delay.

**5.10 What actions can PCTs take if the Fast Track Pathway Tool is being used inappropriately?**

If a PCT 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.

Each individual PCT 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 the 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.

**5.11 How quickly could a discharge take place following the completion of the Fast Track Tool?**

The Responsibilities Directions state that the PCT 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. PCTs 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. PCTs 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. PCTs 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 PCT coordinator and the referrer should communicate effectively with each other to ensure well-coordinated discharge/support provision arrangements.

**5.12 What settings can a Fast Track Pathway Tool be used in?**

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 urgent package of support in their preferred location. This includes where such urgent 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.

The setting is not the most important issue but rather that the individual concerned receives the support they need in their preferred place as soon as reasonably practicable.

#### **5.13 Should individuals receiving care via the Fast Track Pathway Tool have their eligibility for NHS continuing healthcare reviewed?**

The aim of the Fast Track Pathway Tool is to get an appropriate 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 doing this, there may be certain cases where the needs indicate that it is appropriate to review eligibility for NHS continuing healthcare funding.

PCTs 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. PCTs should monitor care packages to consider when and whether a review is appropriate.

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.

Eligibility for NHS continuing healthcare can only be ended by a review through the use of the full MDT-led DST process. PCTs are reminded that any decision to remove eligibility for continuing healthcare should be undertaken jointly involving the PCT and the relevant LA. (The Ordinary Residence Guidance 2010 should be used to identify the relevant social services authority). Where an MDT cannot reach agreement on whether NHS continuing healthcare eligibility should continue when reviewing a Fast Track case, the local disputes process as required by the Responsibilities Directions should be used to resolve the matter. There should be a clear written agreement on any transfer of responsibility that ensures continuity of care/support for the individual. The individual affected should be notified of the proposed change in writing and given an opportunity to submit views before the final decision is taken. When the final decision is made, they should be given details of their right to request an independent 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.

## 6. Screening for NHS Continuing Healthcare – the Use of the Checklist Tool

### 6.1 What is the NHS continuing healthcare Checklist?

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.

### 6.2 Does everyone need to have a Checklist completed?

No, there will be many situations where it is not necessary to complete a Checklist. However, the Responsibilities Directions require PCTs 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.

The Responsibilities Directions state that the Checklist is the only screening tool that can be used. PCTs 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 PCT 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.

LAs have a duty to notify the NHS and invite them to assist in the completion of a community care assessment<sup>14</sup> 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

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<sup>14</sup> See section 47(2) of the NHS and Community Care Act 1990 which can be found at [http://opsi.gov.uk/acts/acts1990/Ukpga\\_19900019\\_en\\_1](http://opsi.gov.uk/acts/acts1990/Ukpga_19900019_en_1)

review stage will ensure that people presenting to the LA with health-related needs are properly considered for NHS continuing healthcare eligibility.

### **6.3 Who can complete a Checklist?**

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 PCT 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.

### **6.4 When should a Checklist be completed if the individual is in hospital?**

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. Section 7 below 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 continuing healthcare eligibility. This should be considered before completion of the Checklist as well as before completion of the DST.

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.

PCTs 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.

**Good practice note:** 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 PCT. 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 PCT 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 PCT and the individual should be kept fully informed of the changed position. This process will enable the PCT to redirect their resources to where they are most urgently required.

#### **6.5 When should the Checklist be completed if the individual is in the community or in a care setting other than hospital?**

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.

#### **6.6 Who needs to be present when a Checklist is completed?**

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. Those completing Checklists should be

aware of the circumstances when an IMCA should be involved at an early stage in the assessment process as set out above (see 3.6).

The individual themselves should normally be present at the completion of the Checklist, together with any representative in accordance with the above.

#### **6.7 What information needs to be given to the individual when completing a Checklist?**

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 PCT in case they want to challenge the Checklist decision (including any review processes available through the PCT 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. PCTs should consider making the decision available in alternative formats where this is appropriate to the individual's needs.

#### **6.8 What should happen once the Checklist has been completed?**

If full consideration for NHS continuing healthcare is required the Checklist should be sent to the PCT where the individual's GP is registered unless alternative arrangements have been made by the PCT. If the individual does not have a GP, the responsible PCT should be identified using the approaches set out in the Who Pays guidance<sup>15</sup>. The Checklist 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

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<sup>15</sup> [http://www.dh.gov.uk/dr\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_079724.pdf](http://www.dh.gov.uk/dr_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_079724.pdf)

of the Checklist and should only be used if no other referral mechanism is available. Each PCT should have appropriate secure arrangements for the receipt of Checklists and these should be publicised to all relevant partners. The PCT 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.

PCTs 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 PCT 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 the PCT has the ultimate responsibility.

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 PCT for information, as the individual may wish to request the PCT to reconsider the decision and the PCT will need a copy of the Checklist in order to do this.

#### **6.9 What evidence is required for completion of the Checklist?**

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 in-patient 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.

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.

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 PCT to understand why the decision was reached. Providing as much information as possible will also support the PCT coordinator to put arrangements in place quickly when they receive the Checklist.

#### **6.10 Can registered nurses in care home settings complete a Checklist Tool?**

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 PCT continuing healthcare team and ask for a Checklist to be completed, unless the PCT has protocols in place setting out other arrangements for completion of Checklists in these circumstances.

#### **6.11 Can someone self-refer by completing a Checklist themselves?**

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 PCT 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 PCT on their behalf. Where the need for a Checklist is brought to the attention of the PCT 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.

#### **6.12 What is the role of the continuing healthcare coordinator?**

Once an individual has been referred for full assessment for NHS continuing healthcare, the PCT has the responsibility for coordinating the whole process until the eligibility decision is made. The PCT should identify an individual or individuals to carry out the coordination role. Whilst this is likely to be a PCT 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.

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.

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

#### **6.13 How long should the assessment and eligibility decision-making process take (for non-fast-track cases)?**

The assessment and decision-making should take place as soon as reasonably practicable and in most cases within the 28 calendar days specified in the Framework (from the date the PCT receives the referral to the date that the eligibility decision is made). The PCT should inform the individual of the decision immediately. It is not acceptable for individuals to be waiting extended periods of time for decisions to be made or given about their future care/support needs, as this is potentially one of the most significant life-changing events for them. Therefore, practitioners need to work closely together to ensure this process is completed as smoothly and quickly as possible to enable the individual to receive the care package they require.

# 7. Hospital Discharge Policy and Interim Processes

## 7.1 How does NHS continuing healthcare fit with hospital discharge procedures?

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, PCTs 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.

The Delayed Discharges (Continuing Care) Directions 2009 places certain responsibilities upon both PCTs and NHS Trusts in hospital discharge situations. Where such dual responsibilities exist, PCTs and NHS Trusts should ensure that their respective responsibilities are agreed and identified in local protocols. PCTs should also ensure that discharge policies with providers who are not NHS Trusts are clear on the respective responsibilities of the PCT and of the provider. Where appropriate, the PCT may wish to make appropriate provisions in its contract with the provider.

The 'delayed discharges' procedures (such as the issuing of section 2 and section 5 notices under the Community Care (Delayed Discharges etc.) Act 2003) are not triggered until the NHS body is satisfied that the relevant individual is not entitled to NHS continuing healthcare. The Delayed Discharges (Continuing Care) Directions 2009 state (in directions 2(1) and 2(2)) that before an NHS body gives notice under the Community Care (Delayed Discharges etc.) Act 2003 of an individual's case to a LA, 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. (See also 2.2 above regarding LA responsibilities in these circumstances.)

Where it appears to an NHS body 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.

The Framework states that 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 (see paragraph 57 of the Framework). Where a person is discharged from hospital with such interim services in place delayed discharges legislation does not apply.

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.

PCTs 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.

## 7.2 **How does NHS continuing healthcare link with intermediate care?**

PCTs should have regard to the updated guidance on intermediate care issued in 2009, *Intermediate care – halfway home*.<sup>16</sup>

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

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<sup>16</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_103146](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_103146)

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.

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.

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.

PCTs should seek to ensure that this pathway is followed prior to any long-term placement apart from exceptional circumstances.

## 8. Multidisciplinary Assessment, Completion of the DST and Making Recommendations

### 8.1 Why does the Framework stress that the DST is not an assessment?

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 PCT 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.

### 8.2 What are the elements of a good multidisciplinary assessment?

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 section 3
- > 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.

8.3 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 people,<sup>17</sup> the Care Programme Approach<sup>18</sup> and the Common Assessment Framework.<sup>19</sup> Person-centred plans<sup>20</sup> (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<sup>21</sup> can also provide useful evidence.

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<sup>17</sup> <http://www.dh.gov.uk/en/SocialCare/Chargingandassessment/SingleAssessmentProcess/index.htm>

<sup>18</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_083647](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083647)

<sup>19</sup> <http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/CommonAssessmentFrameworkforAdults/index.htm>

<sup>20</sup> Further details may be found in *Valuing People: A New Strategy for Learning Disability for the 21st Century* at: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4009153](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009153)

<sup>21</sup> Further details may be found in *Health Action Planning and Health Facilitation for people with learning disabilities: good practice guidance* at: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_096505w](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_096505w)

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

**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

#### 8.4 What is a Multidisciplinary team in the context of NHS continuing healthcare?

'Multidisciplinary team' (MDT) has many meanings but in the context of NHS continuing healthcare the Responsibilities Directions 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'.*

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.

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.

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.

MDT members could include:

- > nurse coordinator/assessors
- > social workers/care managers
- > 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.

#### **8.5 What happens if the PCT coordinator is unable to engage relevant professionals to attend an MDT meeting?**

The national framework is clear that PCTs should not make decisions on eligibility in the absence of an MDT recommendation, unless exceptional circumstances require an urgent decision to be made.

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 PCT 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.

If, even after having followed the above processes, there are still difficulties with the participation of, or obtaining assessment information from, a specific professional, PCTs 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. PCTs should record the attempts to secure participation.

In order to ensure effective MDT decision making, PCTs 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.

#### **8.6 Where should an MDT meeting take place?**

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.

#### **8.7 What process should be used by MDTs to ensure consistency when completing the DST?**

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. Having completed the domains

the MDT should consider what this information signifies in terms of the nature, complexity, intensity and unpredictability of the individual's needs. It is important that MDT members approach the completion of DSTs 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 individual's needs.

- 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 on what the eligibility recommendation should be in the light of the DST discussion.
- f) The MDT should then discuss, agree and record their recommendation, based on the concepts in d) above, providing a rationale which explains why the individual does or does not have a primary health need (see below for more detail on recommendations).
- g) The recommendation should then be presented to the PCT, 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 PCT, exceptionally, does not accept the MDT recommendation (see 9.3 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 PCT 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 PCT 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.

## **8.8 What happens if MDT members cannot agree on the levels within the domains of the DST?**

The Framework 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 PCTs can note this when verifying recommendations.

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 PCT 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.

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 PCT 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.

## **8.9 What happens if the individual concerned or their representative disagrees with any domain level when the DST is completed?**

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 8.8 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.

#### 8.10 What does the DST recommendation need to cover?

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 section 4 of this guidance
- 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 section 4 of this guidance). 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.

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).

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.

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 29 of the 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 PCT who should ensure that the review is arranged at the appropriate time.

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 pre-judged without going through the proper process in each individual case.

All of the above information should be provided even if the recommendation is that the individual does not have a primary health need. The PCT 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 PCT, LA or both will have responsibilities.

The written recommendation needs to provide as much detail as possible, but should be clear and concise, to enable the PCT and the individual to understand the rationale behind the recommendation.

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.

A copy of the completed assessment, DST and other documents should be forwarded to the PCT.

## 9. Eligibility and Panel Processes

### 9.1 If a PCT uses a panel as part of the decision-making process what should its function be and how should it operate?

There is no requirement in the Framework for PCTs to use a panel as part of their decision-making processes. Close working with LA social care is an inherent part of the 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 PCTs to have mechanisms for seeking the views of LA colleagues when making final decisions on continuing healthcare eligibility and this could be by the use of a panel. However the formal decision-making responsibility rests with the PCT. The appendix contains details of the recommended content of local protocols, including decision-making processes.

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 PCT 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).

### 9.2 What should the role of the PCT decision-making process be?

The role of PCT 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 9.3 below
- > agreeing required actions where issues or concerns arise.

PCT 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).

**9.3 What are the 'exceptional circumstances' under which a PCT or panel might not accept an MDT recommendation regarding eligibility for NHS continuing healthcare?**

The Framework (paragraph 80) states '*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.*' The intention is that eligibility decisions should be led by the practitioners who have met and assessed the individual. Exceptional circumstances may therefore 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.

In such cases the matter should be sent back to the MDT for the relevant matters to be addressed. Where there is an urgent need for care/support to be provided the PCT (and LA where relevant) should make appropriate interim arrangements without delay.

**9.4 How should decisions be communicated to the individual/representative?**

Once the recommendation is approved by the PCT, 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.

## 10. Disputes

### 10.1 **There are two different kinds of dispute that may arise in relation to NHS continuing healthcare:**

- a) Disputes between a PCT 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.

On some occasions PCTs 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 PCT should ask them whether this request is in accordance with their wishes, 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.

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

The advice set out in the user notes for the Checklist addresses many of the key issues that may arise in its completion.

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 PCTs.

Where an individual or their representative wishes to challenge a Checklist outcome, they should contact the relevant PCT, using the contact information supplied with the written decision. The PCT 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 PCT may decide to arrange for another Checklist to be completed or to undertake the full DST process, notwithstanding the outcome of the original Checklist.

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

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.

By practitioners working in partnership, and by following this practice guidance (see section 8 above), 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 Responsibilities Directions require each PCT and LA to have a jointly agreed disputes resolution process (in relation to both eligibility for NHS continuing healthcare and joint funding arrangements). Where agreement cannot be reached through the normal eligibility decision-making processes, the formal dispute resolution process should be followed.

Where an individual and/or their representative expresses concern about any aspect of the MDT or DST process, the PCT 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 PCT making the final decision.

### **10.4 What factors need to be considered in local disputes processes?**

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 PCT 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 PCT and LA and agreeing to accept their recommendation.

PCTs 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.

### **10.5 What if the dispute crosses PCT/LA borders?**

Where a dispute occurs between a PCT and LA in different areas (and therefore without a shared disputes resolution agreement) it is recommended that the local process applying to the PCT involved in the case is used. Where a dispute involves two PCTs, it is recommended to use the disputes process for the PCT area where the individual is residing at the outset of the relevant decision-making process. Thus if PCT A had made a placement in PCT B's

area, it is PCT A's dispute process that should be used, even if the person is now physically residing in PCT B. Both PCTs 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 PCT) to oversee the resolution of the dispute.

#### **10.6 What if the individual wishes to challenge the final eligibility decision made by the PCT?**

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 SHA as set out in the Framework. However, PCTs 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, PCTs should continue to seek to informally resolve the matter, up to the date of the IRP hearing itself. When an SHA receives an IRP request they should contact the relevant PCT to establish what efforts have been made to achieve local resolution. SHAs can consider asking PCTs to attempt further local resolution prior to the IRP hearing.

PCTs and SHAs 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 the Responsibilities Directions and so are not a matter for local review or complaints processes. If PCTs and SHAs 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 by writing to the PCT.

PCTs 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.

# 11. Care Planning, Commissioning and Personalisation

## 11.1 How should care planning be approached for a person entitled to NHS continuing healthcare?

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 commissioning processes in PCTs.

*Supporting People with Long-Term Conditions; Commissioning Personalised Care Planning. A Guide for Commissioners<sup>22</sup>* 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

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<sup>22</sup> [http://www.dh.gov.uk/dr\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_093360.pdf](http://www.dh.gov.uk/dr_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093360.pdf)

- > 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.

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

#### 11.2 What are joint packages of care?

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.

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.

In a joint package of care the PCT 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).

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.

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

#### **Practice Example – Joint Package of Care**

A PCT and LA have developed a tool to assist in dividing responsibilities and costs in joint packages of care where the individual is not eligible for NHS continuing healthcare but nonetheless has significant healthcare/nursing needs. This tool draws on the same domains as the DST and asks for each whether the needs identified can lawfully provided by the LA or whether they should be provided by the PCT through existing mainstream provision or through an additional service.

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 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
  - > 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.*

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

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.

As set out in the Framework (paragraph 111), 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 PCT. 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. PCTs should make appropriate arrangements to meet these needs.

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, PCTs 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*.<sup>23</sup> 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, PCTs 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.

PCTs should be aware of their responsibilities and powers to meet housing-related needs for those entitled to NHS continuing healthcare:

- a) PCTs have a general responsibility under section 3(e) of the NHS Act 2006 to provide such after-care services and facilities as they consider appropriate as part of the health services for those who have suffered from illness.

<sup>23</sup> [www.communities.gov.uk/publications/housing/deliveringhousingadaptations](http://www.communities.gov.uk/publications/housing/deliveringhousingadaptations). Fuller details of the powers of housing authorities and partners to provide support can be found in ODPM circular 05/2003 at: [www.communities.gov.uk/documents/corporate/pdf/145088.pdf](http://www.communities.gov.uk/documents/corporate/pdf/145088.pdf)

- b) PCTs 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.
- c) PCTs 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 functions, is affected by any NHS function or are connected with any NHS functions.
- d) Housing can form part of wider partnership arrangements under section 75 of the above Act. Fuller details are available in guidance.<sup>24</sup>

LAs should be aware that they 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 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.<sup>25</sup> 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 PCT on deciding on appropriate equipment/adaptation and whether or not the adaptation is essential to meet the agreed NHS continuing healthcare outcomes.

Whilst LAs and PCTs 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 PCTs 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 PCTs have overlapping powers, in determining responsibilities in an

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<sup>24</sup> [www.dh.gov.uk/dr\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4057423.pdf](http://www.dh.gov.uk/dr_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4057423.pdf) (Although this guidance refers to section 31 of the former Health Act 1999, it continues to be applicable to the replacement power in section 75 of the NHS Act 2006.)

<sup>25</sup> For a fuller discussion on this, see paragraphs 9.62 to 9.66 of the Law Commission's consultation paper on adult social care at: [www.lawcom.gov.uk/docs/cp192.pdf](http://www.lawcom.gov.uk/docs/cp192.pdf)

individual case, PCTs 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 11.8 below.

#### 11.4 Case-Management

Once an individual has been found eligible for NHS continuing healthcare, the PCT 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. PCTs 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.

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.

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 11.1 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

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.

### 11.5 How should commissioning be approached for a person entitled to NHS continuing healthcare?

The Framework sets out a number of responsibilities of PCTs in relation to continuing healthcare commissioning:

- a) Continuing healthcare commissioning should take place within the overall context of World Class Commissioning and involves actions at both strategic and individual levels.
- b) Continuing healthcare commissioning actions by PCTs 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, PCTs 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) PCTs should consider commissioning from a wide range of providers in order to secure high quality, value for money services. In exercising this responsibility, PCTs 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, PCTs should have an understanding of the market costs for care and support within the relevant local area.
- e) PCTs should commission in partnership with LAs wherever appropriate.
- f) PCTs 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 continuing healthcare-funded services is expected to supply should be clearly set out in the contract between the provider and the PCT.

PCTs should commission services using models that maximise personalisation and individual control and that reflect the individual's preferences as far as possible. It is particularly important that this

approach should be taken when an individual who was previously in receipt of an LA direct payment begins to receive NHS continuing healthcare; otherwise they may experience a loss of the control they had previously exercised over their care. PCTs should also be aware of the personal health budgets programme as set out in *Personal Health Budgets: First Steps*<sup>26</sup> 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 PCT to use.

- g) PCTs and LAs should operate person-centred commissioning and procurement arrangements, so that unnecessary changes of provider or of care package do not take place purely because the responsible commissioner has changed.
- h) PCTs should take into account other policies and guidance relevant to the individual's needs.

#### **11.6 Can a PCT use an external agency to carry out the commissioning of continuing healthcare services or for negotiation with providers?**

PCTs hold the statutory responsibility for commissioning NHS services for their populations, including NHS continuing healthcare. Whilst PCTs may reach arrangements with other organisations to carry out functions on their behalf, PCTs retain statutory responsibility.

PCTs can make arrangements with LAs or other bodies/organisations in relation to continuing healthcare commissioning. In order for the LA to commission continuing healthcare on the PCT's behalf, this requires a transfer of appropriate powers using section 75 of the NHS Act 2006. Other arrangements, such as integrated teams of PCT and LA staff commissioning for individuals with high support needs in an integrated manner are also possible. In all cases, PCTs retain ultimate responsibility for continuing healthcare commissioning. Any such arrangements should reflect the PCT's responsibilities to fund the assessed health and social care needs of individuals entitled to continuing healthcare and that continuing healthcare, as with most other NHS services, is free at the point of delivery to the individual.

PCTs should ensure that there is clarity in arrangements with external organisations on the respective responsibilities of the PCT 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 PCT should reflect the best practice set out for PCTs in this practice guidance and in the Framework. The external organisation should operate within the

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<sup>26</sup> [www.dh.gov.uk/dr\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_093839.pdf](http://www.dh.gov.uk/dr_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093839.pdf)

PCT's strategic approaches and policies in relation to continuing healthcare commissioning including in relation to the range of providers and the choice available to individuals.

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

The Framework says (paragraph 100) that *'the package to be provided is that which the PCT assesses is appropriate for the individual's needs'*.

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. PCTs should be aware of the models of support offered by partners and by other PCTs and of evidence about their benefits and risks so that the options offered are maximised and that generalised assumptions are avoided.

In some situations a model of support preferred by the individual will be more expensive than other options. PCTs 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. PCTs should consider whether models such as assistive technology could meet some of these needs. Where individuals are assessed as requiring nursing care, PCTs should identify whether their needs require the actual presence of a nurse at all times or whether the needs are for qualified nursing staff for

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.<sup>27</sup> PCTs 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).

#### **Gunter Case**

In the case of *Gunter vs. South Western Staffordshire PCT*, 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.

#### **11.8 What are the responsibilities of PCTs and LAs when a person is supported in their own home?**

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 PCT 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 11.3), 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 criteria and charging policy, e.g. assistance with property adaptation (see 11.3), support with essential parenting activities, support to access other community

<sup>27</sup> [www.bailii.org/ew/cases/EWHC/Admin/2005/1894.html](http://www.bailii.org/ew/cases/EWHC/Admin/2005/1894.html)

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 11.9 below).

There is a range of circumstances in which PCTs have overlapping powers with other statutory organisations. Where this is the case, PCTs and other statutory bodies should work in partnership locally to determine how each partner's responsibilities will be exercised. PCTs should not simply assume that another organisation will meet the need. Active liaison should take place. The needs appropriate for the PCT 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.

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 PCT 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 PCT or a partner organisation did not fund/provide the service in question – what would the outcome be?

**11.9 What is the PCT role in relation to carers when someone is in receipt of NHS continuing healthcare?**

When a PCT 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 PCT should give consideration to meeting any training needs that the carer may have to carry out this role. In particular, the PCT 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. Consideration should also be given to referral for a separate carer's assessment by the relevant LA. PCTs have been allocated funding to support carers by DH and through their strategic commissioning they should consider how this funding can best be used to support carers of people eligible for NHS continuing healthcare.

**11.10 Can a personal health budget be used for people eligible for NHS continuing healthcare?**

Yes, and PCTs 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 PCT commissioner
- > a budget managed on the individual's behalf by a third party, and
- > a cash payment to the individual (a 'healthcare direct payment').

Direct payments for healthcare can only be offered by PCTs that are pilot sites approved by the Secretary of State. However PCTs 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*.

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

A wide variety of resources are available via the personal health budgets learning network website at [www.dhcarenetworks.org.uk/PHBLN/](http://www.dhcarenetworks.org.uk/PHBLN/). This includes a range of resources to support personalised commissioning generally beyond personal health budgets. PCTs 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. PCTs 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.

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

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.

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.

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.

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.

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.

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.

Susan agreed to take part in a local personalisation pilot with her PCT. 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.

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.

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.

**11.13 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**

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. 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.

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.

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 PCT 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 PCT. 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.

A multidisciplinary review is held. The PCT funds an advocate for David to support him in the review. It is identified that Supporting People funding is not affected by continuing healthcare entitlement so can continue in place. Arrangements are made for the PCT 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.

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 PCT, 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 PCT. A protocol is developed between the PCT, the support provider and David which states that David oversees the day-to-day activities of the support worker.

**11.14 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?**

The LAs and PCTs taking part in the personal health budget pilots 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 PCTs 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 PCTs 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.

An advice note on personal budgets in social care has recently been jointly published by the Association of Directors of Adult Social Services, the Local Government Association and the Improvement and Development Agency.<sup>28</sup> It is primarily focused on providing clarity and improving understanding of managed personal budgets (where people opt to continue to use services commissioned by the council), where confusion has arisen and where there is concern that councils are setting up arrangements that do not properly support the choice and control aspirations of personalisation. DH will also be issuing further guidance on personal health budgets later this year and sharing early learning from the pilot sites through the learning network.

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

DH published guidance<sup>29</sup> (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 secondary and specialist care services, 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.*
- 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.*

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<sup>28</sup> [www.adass.org.uk/images/stories/Personal Budgets \\_ Council Commissioned Services – Advice Note.pdf](http://www.adass.org.uk/images/stories/Personal_Budgets_-_Council_Commissioned_Services_-_Advice_Note.pdf)

<sup>29</sup> [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAnd Guidance/DH\\_096428](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_096428)

*To avoid these risks, there should be as clear a separation as possible between private and NHS care.*

PCTs 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 PCT for consideration.

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 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 been 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, PCTs 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, PCTs should offer to review the care package in order to identify whether a different package would more appropriately meet the individual's assessed needs.
- > PCTs 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 PCT. In developing or reviewing care packages, PCTs should consider whether other services commissioned or provided by the PCT 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' was 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 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 PCT 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 private and NHS care should be carried out in a way which avoids putting individuals receiving services at any unnecessary risk. The PCT, the NHS-funded provider and the private 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 and private 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 private 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.

### **Example**

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 PCT. Eileen considers that she wishes to purchase an additional session of physiotherapy weekly.

The PCT 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.

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.

### **Example**

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 PCT to increase the visits to every two hours. The PCT 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 PCT consider that four-hourly visits are still appropriate during the daytime.

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 PCT 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 PCT, 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.

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

The funding provided by PCTs in NHS continuing healthcare packages should be sufficient to meet the needs identified in the care plan, based on the PCT'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.

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 PCT 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 PCT 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 PCT to meet this.

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 PCT 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 the PCT may propose a move to different accommodation or a change in care provision.

In such situations, PCTs 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.

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 PCT would usually meet for the person's needs, the cost is reasonable taking into account the market rates in the locality of the placement. PCTs should establish this by liaison with the PCT where the placement is located. In such circumstances PCTs 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.

PCTs 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 PCT 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.

Where an individual become entitled to NHS continuing healthcare and has an existing high-cost care package PCTs 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.

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 PCT and the provider.

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 PCT 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.

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 PCT 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.

# Appendices

## APPENDIX A

### 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 in accordance with the *National Framework for NHS Continuing Healthcare and NHS-Funded Nursing Care July 2009 (revised)*, along with the associated tools.

#### **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 access to advocacy for the individual.
- > 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 Responsibilities Directions and is to be acted on by the PCT 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 urgent provision of care/support in fast-track cases, including provision of equipment where necessary.
- > 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.
- > 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.
- > Clarity on how the NHS continuing healthcare process fits with hospital discharge arrangements.
- > 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 PCT 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 over financial assessment and charging if the individual's care/support is currently being funded by the LA during the assessment and eligibility decision-making process.

- > Reviewing arrangements.
- > Timeframes for each stage of the process.

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

### **Decision Making and Panels**

Whilst the Framework does not require the PCT and LA to have a panel arrangement, many areas do use panels as part of the process. However, arrangements should 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.

- > Terms of reference for panel (where this exists) – 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'* (paragraph 80).
- > 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 Resolution between Agencies***

- > 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 PCT 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 both full NHS continuing healthcare eligibility and joint funding arrangements.
- > 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 any guidance on approaches to be taken.



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302166 1p March 10

Produced by COI for the Department of Health

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