Accessing NHS Continuing Health Care

PRACTICAL GUIDANCE FOR THOSE IN NEED OF CARE, THEIR FAMILIES, REPRESENTATIVES AND PROFESSIONAL ADVISERS

In Assocation with

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About My Care Consultant

My Care Consultant (MCC) helps those in need of care navigate the complex social and health care system, understand the value of professional financial, legal and property management advice and facilitate access to it. In doing this, MCC seeks to establish a clear pathway, a joined up approach and to be an independent 'first port of call' in meeting the often complicated and frequently urgent needs that many older people have.

With a deep understanding of the intermediary market, MCC also works closely with financial advisers by providing independent technical and marketing support and consultancy, and by encouraging and supporting participation in the long-term care market. MCC offers practical information and guidance regarding non- regulated care advice and helps advisers combine this with regulated 'paying for care' advice. As a result, advisers can develop comprehensive propositions that better meet the full needs of their clients.

Preface

Much confusion exists surrounding the funding of care for those in later life. At the root of this confusion is often the distinction between social and health care.

Despite the many challenges facing the NHS today, it retains responsibility for delivering health care free at the point of need if there is a 'primary' heath need, irrespective of the financial circumstances of the recipient. Social care on the other hand is the responsibility of Local Authorities and is means tested. The difference between the two is not always clear and this leads to much confusion at what can be a distressing time.

Securing free NHS funded health care is by no means straightforward and some who should qualify for this support don't receive it. Eligibility criteria are complex and inexact, the information available is often confusing and hard to find, and attainment and delivery is fraught with inconsistencies. At the same time, social care is being cut back and some welfare benefits restricted, making legitimate access to NHS Continuing Health Care provision increasingly important.

This guide attempts to bring much needed clarity. It aims to make it easier for those in need of health care to identify whether they are eligible for NHS Continuing Health Care funding and if so, to help them secure such funding. It is based on our understanding of legislation, rules and regulations that apply to those living in England. It does not attempt to provide answers to all questions, many of which will relate to individual circumstances, but it does try to simplify navigation of a complex and often confusing system and to help the reader understand some of the key issues to consider and questions they should ask. Indeed, we hope it will provide an invaluable first 'port of call' for those in need of care, their carers, representatives and advisers.

Jacqueline Berry, Founder

My Care Consultant Ltd

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Section 1 - Understanding the Basics

WHAT IS THE DIFFERENCE BETWEEN SOCIAL CARE AND HEALTH CARE?

Whilst there is no formal definition of Social Care, it is often described as dealing with the "activities of daily living". In other words, help that is needed to carry out day to day activities like eating, washing, dressing, mobility and using the toilet. It also refers to help needed to maintain independence, social interaction, manage complex relationships and to be protected in vulnerable situations.

Eligibility for social care is means tested and is the responsibility of the Local Authority

In contrast, a healthcare need is one related to the treatment, control or prevention of a disease, illness, injury or disability and the after care of someone with these conditions. Whilst not defined in law, this definition of healthcare needs is set out in what is known as the National Framework for NHS Continuing Healthcare and NHS Funded Nursing Care (November 2012 Revised).

The National Framework establishes that where the primary need for care is a health need, then the responsibility for providing for that health need lies with the NHS and is free at the point of need, whether the individual is in a Local Authority care home, a private nursing home, or receiving care at home.

WHAT IS NHS CONTINUING HEALTH CARE AND WHO IS ELIGIBLE?

'NHS continuing healthcare' (NHS CHC), sometimes referred to as 'NHS continuing care' or 'fully funded NHS care', is the term used when the NHS is responsible for paying for the care and support required by an individual with ongoing health care needs (referred to as having a 'primary health need') outside of hospital. Such care can be provided to any individual aged 18 or over, to meet needs that have arisen because of disability, accident or illness.

Where an individual qualifies for NHS CHC the funding of their whole package of assessed care, including accommodation if needed, becomes the responsibility of the relevant Clinical Commissioning Group (CCG) as opposed to the Local Authority's Social Services department. Eligibility for NHS CHC places no limits on the settings in which the package of support can be offered or on the type of service delivery.

WHAT IS A 'PRIMARY HEALTH NEED'?

An individual is deemed to have a primary health need if, considering all their needs, the main aspect of the care they require is focused on addressing and/or preventing health needs.

A primary health need is not about the reason why someone requires care or support, nor is it based on a diagnosis; it is about the level and type of actual day-to-day care required and it is the nature and intensity of these needs that must be considered when determining eligibility for NHS CHC.

If someone does not qualify for NHS CHC the NHS may still have a responsibility to contribute towards meeting that individual's health needs – either by directly commissioning services or by part-funding the package of support.

WHAT IS NHS-FUNDED NURSING CARE?

'NHS-funded nursing care' (sometimes referred to under the old name of 'Registered Nursing Care Contribution') is the funding provided by the NHS and paid directly to those residential homes that have a registered nurse present and can therefor support the provision of nursing care. It is a flat rate contribution which was £156.25 per week, but this was reduced to £155.05 on 1st April 2017. NHS-funded nursing care is paid at the same rate across England. The current rate is being paid on an interim basis whilst further work is done to review the element of the rate for agency nursing staff and to consult on the possibility of introducing regional variations in the near future .

NHS-funded nursing care should be received if:

- The individual is resident in a care home that is registered to provide nursing care; and
- They do not qualify for NHS CHC but have been assessed as requiring the services of a registered nurse

In all cases eligibility for NHS CHC should be considered and duly assessed before any decision is made about the need for NHS-funded nursing care.

WHAT IS A 'JOINT PACKAGE OF CARE?'

A joint package of care is where the cost of an agreed care package is funded by both a Local Authority and a CCG. A joint package of care could include NHS-funded nursing care and other NHS services that are beyond the powers of a Local Authority to meet. Joint packages of care may be provided in a nursing or residential care home, or in someone's own home.

WHAT ARE THE PRINCIPLES AND PROCESSES THAT GOVERN NHS CHC?

These are set out in what is known as the National Framework, that govern NHS CHC and NHS-funded nursing care. Full details of the National Framework can be found online (see Section 6 - Further Information and Key Guidance Documentation - The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care *November 2012 (Revised)*)

This Department of Health document concentrates mainly on the process for establishing eligibility for NHS continuing healthcare and the principles of care planning and dispute resolution relevant to that process. It doesn't specify every detail relating to the planning of NHS CHC. It clarifies the interaction between assessment for NHS CHC and the assessment for NHS funded nursing care. It also attempts to minimise the possibility of different local interpretations and help improve the transparency and consistency of the decision-making process.

The National Framework also includes a section on what eligibility should not be based on, and this includes:

- an individual's diagnosis
- where care is to take place
- the ability of the care provider to manage care
- the use (or not) of NHS-employed staff to provide care
- the need for/presence of 'specialist staff' in care delivery
- the fact that the need is well managed
- the existence of other NHS-funded care
- any other input-related (rather than needs-related) rationale

WHO IS RESPONSIBLE FOR NHS CHC?

CCGs and the NHS Commissioning Board assumed responsibilities for NHS CHC from Primary Care Trusts (PCTS) from 1 April 2013. NHS England has commissioning responsibilities for some specified groups of people (e.g. prisoners and military personnel)

Each GP practice is a member of a CCG which manages the process for patients registered with its member practices. The CCG makes eligibility decisions, funding decisions and unless the individual has chosen to have a personal health budget, the CCG will also arrange the care package. Eligibility decisions must be made quite independent of a CCG's budget constraints. Each CCG has a manager responsible for NHS CHC.

To identify the appropriate CCG, the postcode of an individual's GP practice can be entered into the NHS Choices website:

www.nhs.uk/Service-Search/Clinical-CommissioningGroup/LocationSearch/1

As many decisions regarding NHS CHC are made at a local level, people across the country can have very different experiences and sometimes outcomes. Whilst the National Framework has tried to reduce these variations, they do still exist. To provide clarity on the operational processes that underpin the framework, NHS England developed the CCG Assurance Framework, which was replaced by the new CCG Improvement and Assessment Framework (2016/2017). This framework attempts to improve the performance of CCGs by laying out how they should perform (it is a set of guidelines however, not a legal requirement).

NHS CHC funding must cover all assessed care needs regardless of where the individual will be receiving that care. Due to budget difficulties some CCGs may try to impose a financial limit above which they will not pay for care. This must not lead to any aspects of the required care not being provided and paid for. However it *can* mean that the CCG insists that the identified needs are met in the most cost-effective way they can find, rather than in the individual's preferred way, and unfortunately NHS CHC funding cannot be topped up by the recipient or their representatives. Such top ups are only relevant to local authority means tested care.

Remember that when an individual receives NHS CHC it's because their health-care needs are such that they require NHS care and the NHS is legally responsible for paying – even if the actual care given is provided by a private care home/care provider and not directly by the NHS.

WHAT ABOUT NHS CHC FOLLOWING DISCHARGE FROM HOSPITAL?

The Care Act (2014) requires proper consideration of NHS CHC before someone is discharged from hospital. However, it is becoming more common to hear of "discharge to assess" procedures being used given the current pressure on hospital beds. This can lead to an increased chance of the assessment being limited, or even missed.

"Discharge to assess" (also sometimes referred to as 'home first' or 'safely home') is designed to provide short term, funded support so that an individual who no longer requires an acute hospital bed is discharged to their own home (where appropriate) or another community setting. Assessment for longer-term care and support needs is then undertaken in the most appropriate setting and at the right time for the individual.

The National Framework for NHS Continuing Healthcare guidelines also states that the Checklists should not be completed at too early a stage in an individual's hospital stay. Similarly, the speed of discharge should not be used as a reason not to follow proper Checklist procedure as this could mean the discharge process is unsafe as the individual's ongoing care needs have not been taken into account.

WHAT ABOUT SECTION 117 OF THE MENTAL HEALTH ACT?

Where an individual is subject to Section 117 of the Mental Health Act 1983 and requires mental health related aftercare, the NHS and Local Authority have a statutory and joint responsibility to arrange and fund such support based on their local arrangements. This is treated quite separately to the individual's more general health care needs. As such, an individual subject to Section 117 should only be considered for NHS CHC where they have significant healthcare needs which are not related to their mental health aftercare.

Section 2- Getting to grips with the Assessment process

THE FUNDAMENTALS

The eligibility assessment process takes place at the interface between health and social care, setting out funding and provision responsibilities. The fundamental principle behind the NHS CHC assessment process is to ascertain whether an individual's needs are above or below the legal limit for local authority care. If the NHS pushes responsibility for care onto a local authority, and claims that the care needs are just social care needs, it risks putting the local authority in an illegal position; at the same time, the NHS fails in its duty to provide nursing care free at the point of need.

Although there are situations where it is deemed unnecessary to consider eligibility for NHS CHC, the Local Authority (usually via a social worker) has a legal duty under the Care Act to refer an individual for a Continuing Healthcare assessment if there is even a small chance that they may be eligible. The CCG must also take reasonable steps to ensure individuals are assessed where it appears such a need may exist.

Although the NHS CHC process is largely about funding, it is also designed to identify current and ongoing care needs. In Continuing Healthcare funding assessments, most NHS assessors start with the premise that the person being assessed must be shown to have a 'primary health need' – and if they don't then by default they will be regarded as having only a social care need. In such instances the individual is then means tested. However, from the implementation of the NHS Act 1946 and the National Assistance Act (NAA) 1948, if a person has care needs that are more than simply social care then by default they have a health care need – and the NHS should provide funding.

REPRESENTATION AND ADVOCACY

Any individual being considered for NHS CHC is entitled to nominate an advocate who can speak on their behalf, can represent their views and is there to support them. This could be a friend, family member, a local advocacy service or someone independent who has an advocacy role.

Where an individual appears to lack mental capacity, the principles and processes specified in the Mental Capacity Act (MCA) 2005 apply. Where mental capacity deteriorates to the extent that it is determined that they don't have the capacity to make decisions for themselves, their representative or advocate must hold one of the following documents:

- A Lasting Power of Attorney which has been registered with the Office of the Public Guardian. This can be either a Health and Welfare Lasting Power of Attorney or a Property and Financial Affairs Lasting Power of Attorney, or both.

- An Enduring Power of Attorney which has been registered with the Office of the Public Guardian .
- An order of the Court of Protection appointing them as Deputy and where the order enables them to decide to request a review of an eligibility decision.

There is sometimes confusion as to which type of LPA is relevant ('property and financial affairs' or one for 'health and welfare'). If someone has completed and registered a LPA for property and financial affairs, the attorney has the legal power to make financial decisions on their behalf. However, an attorney can only access the person's medical notes for financial reasons (often needed for them to carry out their role). If the attorney thinks that the person is entitled to NHS continuing healthcare, this should be considered a financial reason although there is some online evidence to suggest some assessors may only accept an LPA for health and welfare to access a person's medical records.

Section PG7.3 of the National Framework states:

"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"

However, according to Age UK (Factsheet 20 – Nov 2016) there are circumstances where it is deemed acceptable for a third party acting in a person's 'best interests' but without the formal authority of an LPA 'health and welfare' to legitimately request and receive information, such as someone with an LPA 'property and financial affairs' seeking to challenge an eligibility decision.

Where an individual has appointed an attorney through either an EPA or appropriate LPA, all the health and social care authorities should keep them informed and involved at every stage.

Appealing an NHS CHC assessment can be challenging, although not impossible to do independently. If the individual or their representatives feel the need to make use of advocacy, either initially or to help with an appeal, we recommend finding an individual or organization with the right level of practical expertise and hands-on experience in this area.

STAGE ONE - THE CHECKLIST

The Checklist is the first stage of the NHS CHC funding assessment process. Keep in mind that the Checklist can be completed by just one person (a health or social care professional who understands the process, who understands the reason for the Checklist and who has a good understanding of the nature and extent of the care needs of the person being assessed)

According to NHS England's 'Guide for Health and Social care practitioners' (September 2014), health and social care staff should always consider using the Checklist in the following circumstances:

- at health or social care assessments and/or reviews where the individual has significant health needs
- before any NHS-funded Nursing Care assessment and at each review
- whenever an individual is placed in a care home
- when an individual is to be discharged from hospital (acute, community or mental health) and requires an ongoing placement or substantial package of care
- whenever it appears that an individual may potentially need NHS CHC

In addition, Age UK suggest (See Section 6 – link to Factsheet 20 - NHS continuing healthcare and NHS-funded nursing care November 2016) consideration should also be given to using the Checklist :

- at the end of a period of intermediate care, rehabilitation or other NHS services and no further improvement in condition is likely
- if physical or mental health deteriorates significantly and the current level of care – at home or in a care home – seems inadequate
- when, as a nursing home resident, staff review the individual's nursing care needs. This should happen at least annually.
- if the individual's condition is rapidly deteriorating and they may be approaching the end of life – in this case they may be eligible for 'fast tracking'.

The individual being assessed, and/or any representatives acting on their behalf, should be involved at every stage and asked for their input. They should also be given sufficient notice of any assessment dates, along with accurate information about the process, how it works and what the eligibility criteria are. Also, the individual's consent should always be obtained before the process of working through the Checklist commences.

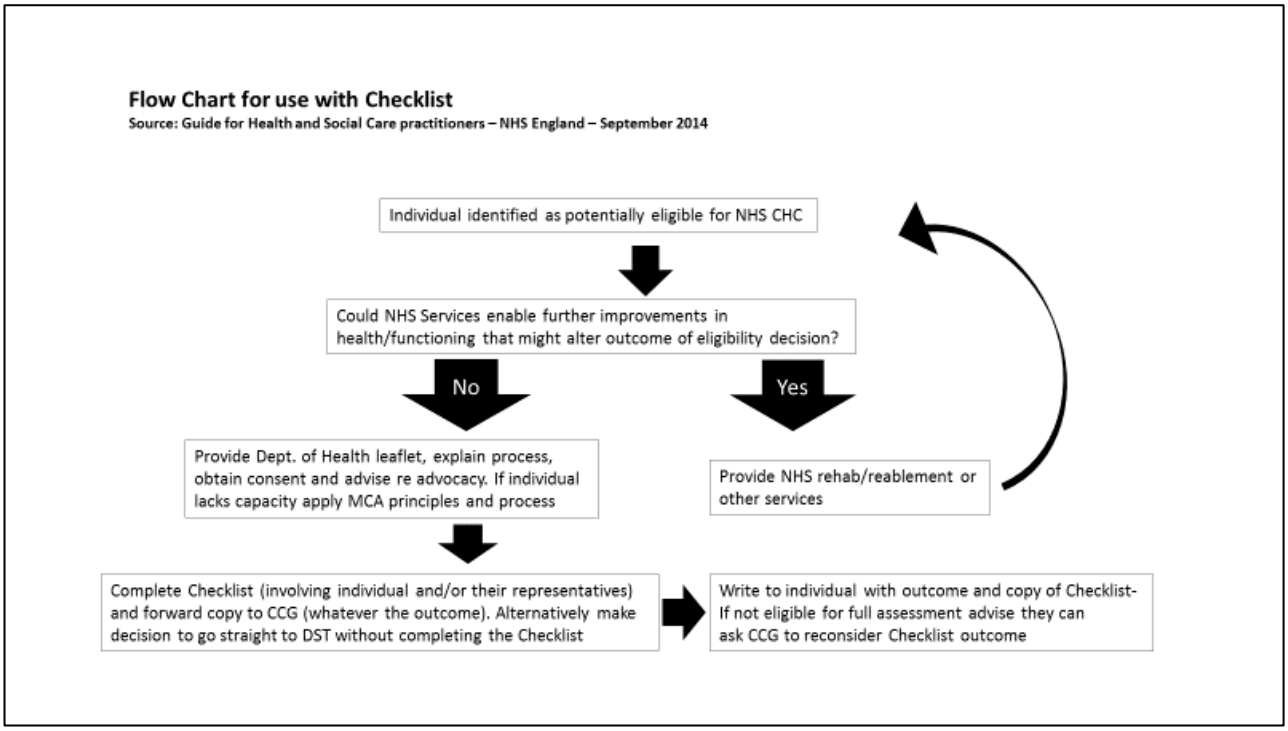
The Checklist does not involve a multidisciplinary team (MDT) and does not need to go to a CCG decision-making panel. Instead it is sent to the Continuing Healthcare team, which is based at the CCG. The assessment process is sometimes outsourced to a Commissioning Support Unit (CSU), but it is still the CCG that retains the decision-making responsibility for NHS CHC funding. Good practice (Framework practice guidance) suggests that both health and social care assessments should be considered to complete the checklist properly.

If, having completed the Checklist, it is decided that the individual is **not** eligible for NHS CHC funding, bear in mind that this decision is not permanent. It can be overturned later if a review shows that their needs have changed. If the individual or their representatives disagree with the decision, they can request another Checklist assessment by contacting their local NHS Continuing Healthcare team in writing

asking for the Checklist to be repeated and giving reasons why. Alternatively, they can request **a full** assessment which is much more detailed (stage two – see below).

Assessments should be carried out transparently and the individual and their legal representatives should be kept informed. They should not be subject to immediate and inappropriate pressure to submit to a financial assessment. Financial means-testing should never be part of the decision-making process about eligibility for NHS CHC. Nor should NHS budgetary considerations influence eligibility decisions.

A positive outcome in the Checklist does not mean the individual is automatically eligible for NHS CHC funding; it simply means that they progress to stage two (see below). Stage two involves a Multidisciplinary Team (MDT) and the use of the Decision Support Tool (DST) ; this stage is often known as the 'full assessment' and it is much more involved.



STAGE TWO – THE MULTIDISCIPLINARY TEAM (MDT) ASSESSMENT/THE DECISION SUPPORT TOOL (DST)

If an individual has got through the initial Continuing Healthcare Checklist assessment (stage one) with the required 'scores', they are put through to stage two, the Multidisciplinary Team (MDT) assessment.

A MDT is defined as:

- two professionals from different health professions or
- one professional from a healthcare profession and one who is responsible for assessing individuals for community care services.

Although an MDT can simply comprise two professionals from different healthcare professions, the National Framework makes clear that it should usually include both health and social care professionals who are knowledgeable about the individual's health and social care needs. This will also ensure a judgment can be made by the local authority about whether the person's care needs are beyond those for which the local authority can legally take responsibility (in other words, to help determine on which side of the legal NHS/local authority divide the person falls).

If the NHS hasn't invited the local authority to attend the MDT meeting (e.g. via a social care professional), the individual or their representatives should consider contacting the local authority themselves (by writing to the Head of Adult Care and the relevant social worker contact). The local authority risks acting illegally if they allow the NHS to pass responsibility to the local authority without thorough assessment of the extent of the care needs.

The names, job titles and signatures of multidisciplinary team members should be recorded on the DST form.

This assessment has nothing to do with whether the person currently has sufficient money/assets to pay for their own care or whether the person is currently paying for their care. It is only if a person's needs are within the scope of local authority social care that they should ever be means tested and potentially end up self-funding.

A good MDT decision must explore the views and input of everyone involved, including the local authority. If this does not happen, it may be impossible to reach a reasoned and accurate conclusion

Stage two involves a form called the 'Decision Support Tool' (DST) which is completed by the MDT, not just by one person. This is a supporting document, as the members of the MDT do not have the power to make the actual funding decision; instead, they make a recommendation, based upon and backed up by the DST, and this is passed to a decision-making panel for the final decision.

The DST aims to bring together and record a person's needs based on 12 'care domains':

1. Behavior

2. Cognition

3. Psychological/emotional needs

4. Communication

5. Mobility

6. Nutrition–food and drink

7. Continence

8. Skin (including tissue viability)

9. Breathing

10. Drug therapies and medication: symptom control

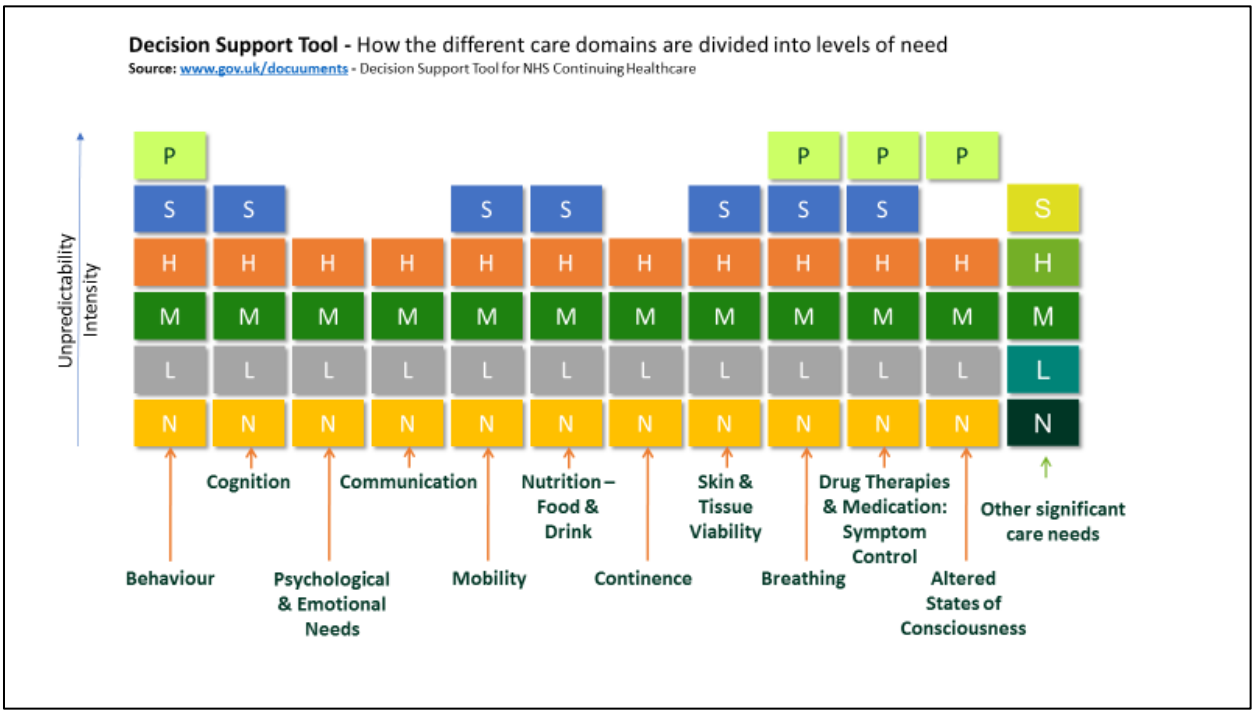
11. Altered states of consciousness

12. Other significant care needs.

The individual is assessed on their needs in each of the twelve domains, which are scored as having low (L), moderate (M), high (H), severe (S) or priority (P) needs. As can be seen in the diagram below, not all domains have the full range of scores available – so while the highest level of need in the Continence domain would be scored as "High", some domains can be scored as "Severe" or "Priority" at their highest level. Each domain is explained in full in the notes that accompany the DST.

There is no specific combination of scores that will 'guarantee' eligibility, however, a clear recommendation of eligibility to NHS continuing healthcare would be expected in each of the following cases:

- Where the level "priority" has been given to the needs required in any domain.
- A total of two or more incidences of identified severe needs across all care domains.



An indication of a primary health need *may* arise where:

- one domain is recorded as severe, together with needs in several other domains, or
- several domains are recorded as having high and/or moderate needs.

In such cases the overall level of need, the interactions between needs in different care domains, and evidence from risk assessments should all be considered when deciding whether a recommendation of eligibility for NHS continuing healthcare should be made. Put another way, the DST is not an assessment in itself, but is more a way of testing for the presence of a primary health by collating evidence in a reliable format to improve consistency and to ensure decisions are evidence based.

Reaching a recommendation on whether the individual's primary needs are health needs will also include consideration of:

Nature*:* This describes the characteristics of the individual's needs (physical, mental health, or psychological), and the type of those needs. This also describes the overall effect of those needs on the individual, including the type (quality) of interventions required to manage them.

Intensity: This relates to both the extent (quantity) and severity (degree) of the needs and the support required to meet them, including the need for sustained/ongoing care (continuity).

Complexity: This is concerned with how the needs present and interact to increase the skill needed to monitor the symptoms, treat the condition(s) and/or manage the

care. This can arise with a single condition or can include the presence of multiple conditions or the interactions between two or more conditions.

Unpredictability: This describes the degree to which needs change, the challenges in managing them and the level of risk to the person's health if adequate and timely care is not provided. Someone with an unpredictable healthcare need is likely to have either a fluctuating, unstable or rapidly deteriorating condition.

Each of these characteristics may, in combination or alone, demonstrate a primary health need, because of the quality and/or quantity of care required to meet the individual's needs.

It's important to appreciate that a need should not be minimized or discounted just because it is being successfully managed. Where a need is currently being well managed, this can sometimes lead to it not being rated as highly as it should be in the assessment. If a person has a high level of need, it should be rated as such, even if the need is currently being successfully met.

If someone is found to be eligible for NHS Continuing Healthcare after the full assessment, their primary care need is a health need. Funding will be awarded by the NHS to cover their care costs, including social care costs, such as accommodation in a care home. Funding is backdated to day 29 after the original Checklist was received by the NHS. A further funding review then takes place after 3 months, and from that point on it should be reviewed annually (although depending on circumstances this may be more frequent).

Before any Checklist or DST Assessment is carried out, reasonable notice of the need to undertake the assessment must be given to the person in need of care or (where appropriate) their representative. The process for completion of the assessment should be explained to them and they should be supported to play a full role in the process. They should be given every opportunity to contribute their views about their needs. Decisions and rationales should be transparent from the outset.

All the MDT members involved in the assessment should have their opinions valued equally. The role of the coordinating assessor, also known as the nurse assessor, is to co-ordinate the MDT and to be impartial. They should not dominate discussions and their opinions should not be afforded greater weight than anyone else's.

WHAT IS THE FAST TRACK PATHWAY?

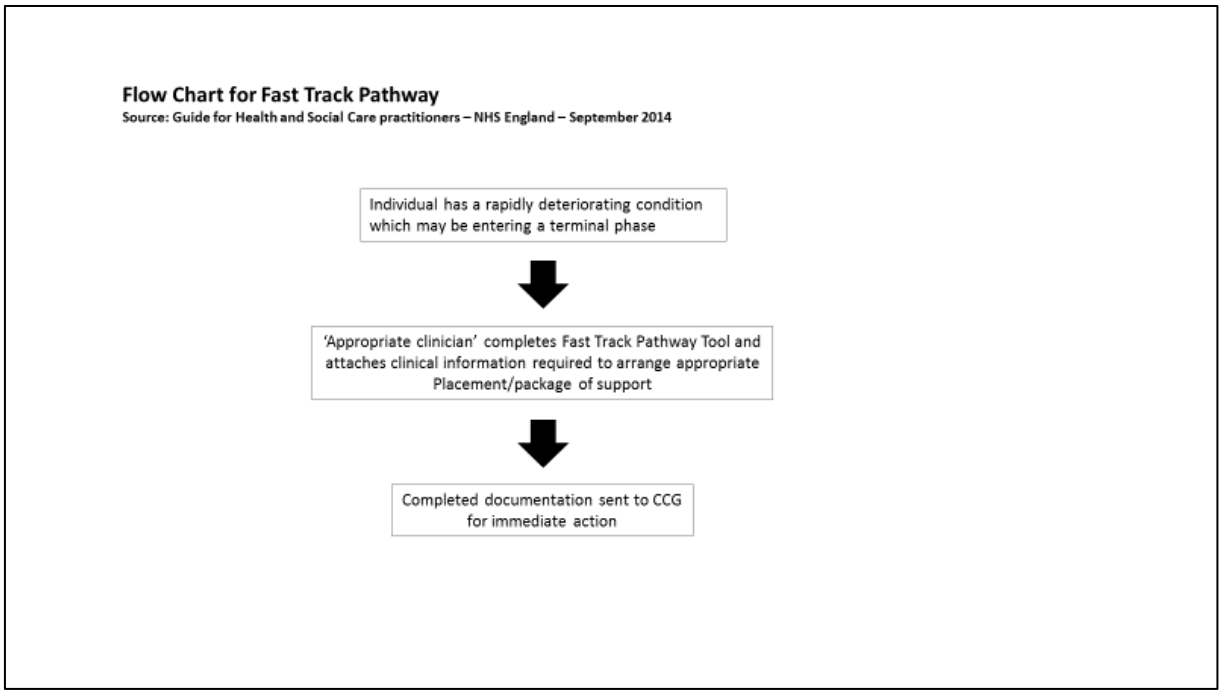
The National Framework also introduced a fast track tool, so that someone who is in very poor health and near the end of their life, can have their eligibility to NHS CHC determined as quickly as possible.

The fast track tool should be used where an appropriate clinician considers that someone should be fast tracked for NHS Continuing Healthcare due to a rapidly

deteriorating condition that may be entering a terminal phase. It is not necessary to predict the time left until a patient dies.

The patient may need NHS Continuing Healthcare funding to enable their needs to be met urgently (e.g. to enable them to go home to die or to provide appropriate end of life support either in their own home or in a care setting).

Whilst the Fast Track tool determines eligibility, a care plan will be required which describes the immediate needs to be met and the patient's preferences. This should be provided alongside the Fast Track documentation, or as soon as practicable thereafter, to enable a CCG or the National Health Service Commissioning Board to commission appropriate care.



WHAT HAPPENS WHEN SOMEONE IS AWARDED NHS CHC?

If someone has navigated the complex process of eligibility and been awarded NHS CHC, the CCG is required to provide a written care plan and to commission an appropriate package of care. There should be no delay in a care plan/package being put in place once the decision to award is received.

However, whilst the National Framework promotes individual choice and control, it only requires CCGs to provide packages of care that they consider to be 'appropriate'. This can result in individuals being told they are eligible for full funding, and then find they have been allocated less care than they have already

been paying for independently. When less funding is allocated, patients can be forced to transfer to a different care provider.

Some CCGs have introduced policies that force people to go into residential care if their care at home is more expensive. For example, a recent newspaper article based on primary research by campaigning group 'Disability United' highlighted that some CCGs will not fund care in a person's own home if it is more than 10% above an alternative. That alternative is usually to go into a care home (The Guardian 27 January 2017). This conflicts with the 'NHS England Operating Model for NHS CHC' and the Department of Health's National Framework for NHS CHC which states that comparative costs must be balanced against a person's desire to continue living in their own home.

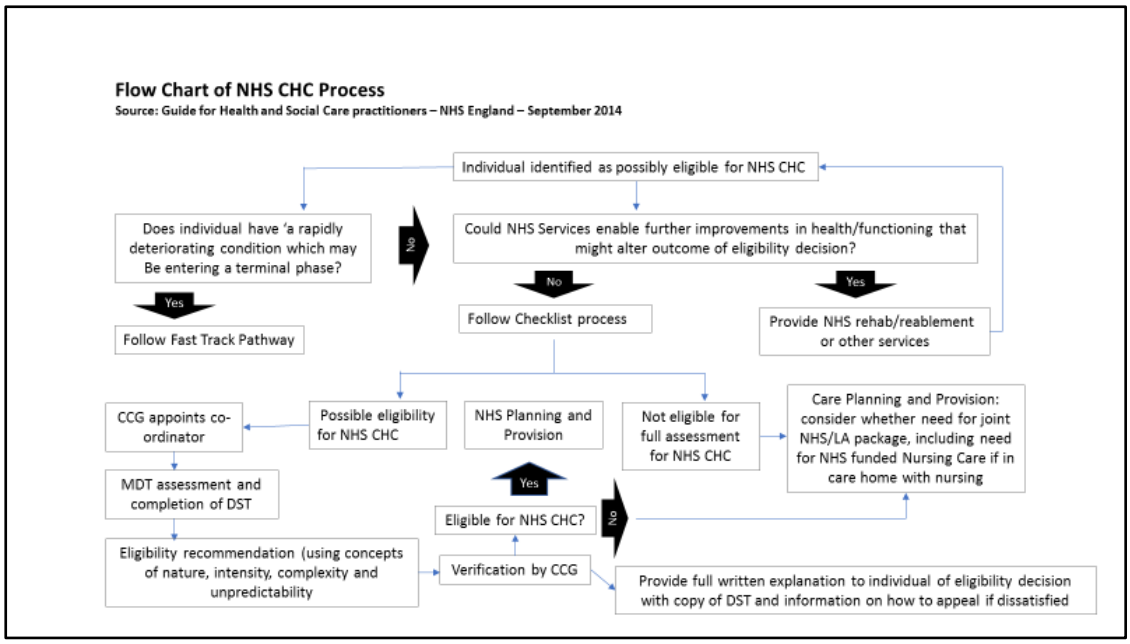
WHAT ARE PERSONAL HEALTH BUDGETS (PHBS)?

A personal health budget is an amount of money that is given directly to an individual receiving NHS care, and is intended to pay for the help and support they receive. Personal health budgets (and personal budgets in social care) aim to give people more choice and control to meet their care and wellbeing needs. Adults eligible for NHS Continuing Healthcare (and children in receipt of continuing care) have the right to have a personal health budget which can be spent on any care or services that are set out in the care and support plan that has been put together with the NHS team working with the person – and this needs to be agreed by the CCG.

More information about PHBs is available from NHS Choices via: www.nhs.uk/personalhealthbudgets

WHAT IF SOMEONE'S CARE NEEDS CHANGE?

CHC is not indefinite as needs can change. If needs change then the NHS CHC funding arrangements may also change. Neither the NHS nor Local Authority should withdraw from an existing care or funding arrangement without a joint review and reassessment of needs. An individual should be informed about any proposed changes, and the NHS and local authority should ensure that alternative funding or services are in place.



DISPUTE RESOLUTION - WHAT CAN BE DONE IF NHS CHC IS NOT AWARDED?

If someone is told they are not eligible and have grounds to believe that this is a mistake, they (or their representatives) can appeal the decision via three progressive stages:

1. Local Dispute Resolution Meeting

If found ineligible at the DST stage, one can submit a Continuing Care appeal via the local NHS. This may result in a Local Dispute Resolution Meeting being offered, but such a meeting may not change the decision, nor involve the NHS in justifying the existing funding decision. One can write to the local NHS Continuing Care Department to disagree with the outcome of the MDT assessment and request a formal appeal. The NHS must adhere to Department of Health's Continuing Care review timescales in dealing with such a request. The applicant should then put in writing all their reasons for disagreeing with the decision to deny Continuing Care funding.

2. Independent Review Panel (IRP)

If the Local Dispute Resolution process results in the decision of 'ineligible' being upheld, one can request that an Independent Review Panel should be convened at regional level. The CCG should provide the information required to request an Independent Review following the Local Dispute Resolution Meeting. An alternative would be to approach the NHS National Commissioning Board or NHS England directly and ask for an Independent Review. This can be done by writing to the NHS Continuing Care Review Panel Administrator at the appropriate regional office of NHS England, disagreeing with the decisions made by the local NHS Clinical

Commissioning Group. The assessments that have been carried out so far should be outlined in such a letter, and a date for an Independent Review Panel hearing (IRP) should be requested.

The role of an Independent Review Panel is to scrutinize, review and advise, but the CCG should accept its recommendation in most cases unless there are exceptional circumstances. The Panel usually includes three decision makers; an independent lay chair (often an academic or legal person who has received appropriate training to chair IRP meetings with impartiality and understanding), a health professional and a social care professional (neither of whom can be from the same CCG who made the original decision). The panel should work together to come to an agreement and may also need to seek the advice of a clinician or specialist in the condition of the person applying.

If those seeking to challenge the funding decision don't go through the Local Dispute Resolution process before asking for an independent review, the NHS may well just send the case back to the local CCG for this to be completed before an Independent Review will be considered

See https://www.youtube.com/watch?v=yiN5cK50FS0 for a video "NHS Continuing Healthcare: what to expect from an independent review panel"

During the whole assessment process, the condition of the individual being assessed can sometimes clearly deteriorate. If this is the case, the local NHS can be asked for a further DST assessment. Also, if the individual is now in 'terminal decline' or in a period of rapid deterioration, a Fast Track assessment can be requested.

If the Independent Review Panel decides that the individual *is* eligible for funding, the NHS Continuing Care funding will be awarded and backdated to shortly after the Checklist was submitted.

3. The Parliamentary and Health Service Ombudsman (PHSO)

For anyone who is found ineligible for funding at the Independent Review, and who still believes this is the wrong decision, the Health Ombudsman can be approached. Failing that, a judicial review/legal action may be pursued. Some may find it helpful to elicit the support of their MP at this stage.

The first two of the above three stages should not normally take more than 12 months to complete but it is not uncommon for some appeals to last considerably longer if all appeals options are explored.

Back in 2012 the Department of Health announced that everyone should have six months to appeal a current or retrospective NHS continuing healthcare decision.

For further details, Beacon (a UK-wide social enterprise) have produced a valuable free appeals guide called 'Beacon Navigational Toolkit – Guide to Continuing Healthcare Appeals' (see Section 6 for contact details)

Section 3 - Retrospective Assessments

There are times when families will want to challenge a decision about NHS CHC assessments which was made some time ago, and which in retrospect they believe to have been wrong. The individual who was assessed may still be in care, or may by now have died. The families and/or legal representatives will be asking whether the person should have been charged for the care they required. In cases like this a retrospective review may be undertaken.

The point of a retrospective review, should it be successful, is to put the individual (or their estate) back into the position they would have been in if NHS Continuing Healthcare had been granted to them at the initial time of assessment.

If the person in question is still alive, it might be decided that there should be a new assessment of their current needs. The individual's representative(s) should be invited to attend. Once the outcome of this assessment is known, its impact on the retrospective review will be considered, and the individual and/ or their representatives will be contacted and advised as to the next stage.

If, after the initial review, it is decided that a full assessment for NHS Continuing Healthcare should be carried out, the CCG will need to collect a great deal of evidence from a variety of sources. At this stage it is difficult to predict how long the review might take as this will depend on how easily available the required evidence is, how lengthy the period of the claim is and the availability of appropriate personnel to undertake the review itself.

If the individual is no longer alive, it can be particularly difficult to carry out such retrospective reviews, particularly when the professionals trying to review the case have never met the person being assessed.

Some of the things to be aware of regarding an NHS Continuing Healthcare retrospective review are:

- When the individual being assessed has already died, the case must rely heavily on written evidence from the past. Such evidence may be of varying quality and accuracy and can be difficult to challenge. The professionals who wrote the evidence may no longer be available to refer to or to clarify their notes and opinions. If care was given in a nursing or residential home, it may have closed down since the period being considered.

- The medical notes and other reports and letters written at the time by those who were responsible for the individual's care may be written in ways that don't fully reflect the real day-to-day needs of the person in care. Such notes are at times quite simple, working notes, designed to be passed between those who are dealing with the care of the individual at the time and who are fully aware of the difficulties and care involved. They may not have been written in a way that can

be relied upon for the kind of detail needed in a retrospective review of the level of care required. As a result, these documents may not particularly help the case for CHC funding.

- The professional carrying out the retrospective review has to produce a Needs Portrayal Document (NPD). This document should clearly describe all of the care needs of the individual during the period that is being reviewed. It is important that this document is carefully checked by everyone involved for inaccuracies or misunderstandings. Any concerns about missing or inaccurate information should be raised as early and clearly as possible.

If the review concludes that the individual was eligible, and should have received funding during all or part of the period being reviewed a restitution payment will be made, in line with the Department of Health Redress Guidance.

If however the conclusion is that the individual was *not* eligible for CHC funding, the applicant will be informed of this and will be sent details of who to contact should they disagree with this outcome.

Most CCGs have their own retrospective NHS CHC departments to process applications but it is not unusual to find that this work is outsourced to Commissioning Support Units (CSUs). Private companies and software platforms have been appointed by some CCGs to administer retrospective NHS CHC cases. This can lead to those pursuing a claim receiving correspondence from organisations that appear to have nothing to do with the situation, so it is important that they know who is dealing with their case. If the case is taken over by a different organisation it is important that the individuals who have requested the review know who and where to send additional, supporting information to, especially when deadlines are tight.

The language and jargon used in the assessment of NHS Continuing Healthcare Funding can be complex and confusing for non health professionals. By learning about it and getting to understand it better, those who are challenging the findings will be in a better position to argue their case. By learning about the Decision Support Tool document (DST) and the domains and definitions within it, they will be better able to describe the care needs in the most appropriate way. The NHS CHC Framework Guidance explains what Nature, Intensity, Complexity and Unpredictability are (see page 12 of this report).These are at least as important as the scores within the healthcare domains.

It is important to understand what may have come under the Local Authority's legal remit, as opposed to what the NHS should have been responsible for.

In a retrospective review, just as in a current needs assessment, it should be clear whether the individual's needs fell within the local authority's legal remit for care or whether those needs were beyond what the Local Authority could legally provide. If

they were within it, the person should have been means tested to see whether they had to pay for some or all of their own care. However if their care needs were beyond what the Local Authority could legally provide, the NHS should have paid for their care through NHS Continuing Healthcare funding.

If the evidence being relied upon, such as care notes, are inadequate or incomplete, the CCG cannot simply decide that this means the person in question should not have received Continuing Healthcare funding.

In an NHS Continuing Healthcare retrospective review, the family or other representative(s) should be consulted and their views and evidence noted usually by way of what is called a Family Statement of Needs. This is where the family can give a written account of what they perceived the care needs of the individual to be. They can explain why they feel their relative should have been receiving NHS Continuing Healthcare funding. If it is to support the case for funding, it should be as clear and detailed as possible, and every care domain should be carefully considered, with a comprehensive description of the challenges, difficulties and needs of the individual being assessed.

If a health professional is asked to write something in support of the case it should be made very clear to them what their statement will be used for. Such statements should be specific, clearly indicating the severity of the care needs involved.

CCGs have many demands on their time and attention, along with time limits imposed upon them by NHS England. They may therefore throw out applications if deadlines are missed by the applicants. This can be frustrating, as the family may have waited months, or even years while the CCG have been gathering evidence, only to be given a few weeks to submit their comments regarding a Needs Portrayal document. These deadlines are not absolute so if the family knows that they will be unable to meet a required deadline, they should get in touch with the requesting organisation in good time and ask for an extension.

The fact that someone has already died does not mean that it is too late to challenge mistakes made by the CCG before the individual's death. The CCG should be able to show that they followed the correct procedure and came to appropriate conclusions. Such decisions can still be overturned if there is suitable evidence to support a case.

See Section 6 - NHS CHC Refreshed Redress Guidance for further information

Section 4 - Understanding the Law

The Care Act 2014 requires proper evaluation of whether a local authority can lawfully provide the services that an individual is deemed to require. If the Local Authority can't, then the care needs have to be seen as reflecting a 'primary health need' and the person is therefore eligible for NHS Continuing Healthcare funding.

The NHS does not have the authority to change the law by introducing internal rules and procedures that will deny an individual their legal rights.

The law is the ultimate arbiter of whether someone is eligible for NHS Continuing Healthcare and overrides any Continuing Healthcare guidelines. Below are details of certain cases in Law, and historical decisions made by the Ombudsman that have been used to support successful claims for NHS CHC. They can and should be referred to, where relevant, in the event of disputed eligibility

THE COUGHLAN CASE 1999 - Court of Appeal Judgment of R v North and East Devon Health Authority

This ruling made it clear that if an individual has healthcare needs that are over and above what Social Services can be expected to provide and are therefore primarily health needs, the NHS has a responsibility to provide for those needs, and to fund the necessary care.

In 1999, Pamela Coughlan won her case for NHS Continuing Healthcare funding at the Court of Appeal. She argued that her full-time care was the responsibility of the NHS to fund, not the local authority. The Court agreed with her, and the Coughlan case became a landmark case in NHS Continuing Healthcare funding.

The eligibility criteria for continuing healthcare applied in the case of Coughlan were judged to be far too restrictive and this judgement resulted in every health authority being instructed to review its local criteria to ensure that it was 'Coughlan compliant'. Essentially this meant that local authorities could only legally provide healthcare services that were:

1. Merely incidental and ancillary to the provision of accommodation which a local authority is already under duty to provide.

2. Of a nature, which it can be expected that an authority whose primary responsibility is to provide social services can be expected to provide.

Despite anecdotal evidence and case studies indicating that some are still told by assessors that the Coughlan case is "out of date" and "no longer applies", it plays a

vital role in ensuring that the NHS doesn't consciously or inadvertently try and pass across funding responsibility and service delivery to the Local Authority.

THE LEEDS CASE 1994 -A complaint to the Health Service Ombudsman against Leeds Royal Infirmary (Case Number: E.62/93-94) in January 1994.

This Ombudsman Report, whilst not legally binding, has provided clarification that it is unreasonable for a health authority to implement a policy that failed to make NHS CHC available where a need for substantial nursing care exists

The patient involved was a man with severe brain damage who was discharged into the community by Leeds General Infirmary with no follow-up care or funding in place. Although his needs had stabilised after 20 months and he did not require active treatment, he still required a significant amount of nursing care for the rest of his life. The health authority did not feel duty bound to continue to provide and fund his care, believing it should be funded from his personal assets so his wife paid for his care in a private nursing home.

The Ombudsman upheld the complaint because Leeds Health Authority had failed to appreciate that a need for substantial nursing was itself sufficient to entitle a patient to NHS continuing healthcare and that it was unreasonable for the authority to implement a policy that failed to make long-term NHS care available.

THE POINTON CASE 2003 - A complaint to the Health Service Ombudsman against a local Primary Care Trust made on behalf of Mr. Pointon (Case Number E.22/02-03).

The ruling led to the principle that NHS continuing healthcare could be provided in any setting, not just care homes with nursing. It also provided confirmation that Alzheimer's Disease was accepted as a 'primary health need'.

Mr Pointon suffered from Alzheimer's disease and had a range of mental and physical health care needs. These included incontinence, cognitive impairment, verbal communication difficulties, inability to feed himself and a requirement for constant supervision and reassurance.

The Ombudsman found that Department of Health guidance had not been properly followed because the continuing healthcare assessment tools used in his case were too focussed on physical needs to the detriment of his psychological needs. Furthermore, Mrs Pointon was providing a high level of personalised care with great skill. The fundamental principle established in this case was that the nursing care provided by Mr Pointon's wife was equal to, if not superior to that which Mr Pointon would have received in a hospital dementia ward.

This challenged the assumption that nursing care can only be provided by qualified nurses. Furthermore, it led to a cultural understanding that assessment toolkits should be needs focussed rather than dependent upon whether the need is being met by a specialist

THE HARINGEY CASE 2005 - The case of R (T, D & B) v Haringey London Borough Council [2005] EWHC 2235.

This ruling held that a local authority could not provide care if the 'scale and type of nursing care' and the purpose of the care were significant- in this case being 'designed to deal with the continuing medical consequences of an operation, which if not met would give rise to urgent or immediate medical needs.'

This concerned patients, who required, amongst other things, maintenance care of a tracheotomy (a tube in the throat). The tubes needed suctioning and replacing regularly and if the tube was not suctioned or became stuck the patient could die within minutes. Patients in this condition could be cared for at home if their carers are trained to carry out the daily routines and cope with the emergencies that may arise. The judge held that a local authority could not provide care of this type, as it was an NHS responsibility.

THE GROGAN CASE 2006 - The case of Grogan vs Bexley Primary Care Trust (2006) 9 CCLR 188

This ruling ultimately established important principles such as the requirement of PCTs to assess all the individual's relevant needs rather than only their nursing needs as well as clarification in respect of the interaction between continuing healthcare and the registered nursing care contribution (RNCC). In all cases decision makers should establish whether an individual was eligible for continuing healthcare before considering which RNCC banding to apply to their care.

In the case of Grogan vs Bexley Primary Care Trust the High Court ruled that eligibility criteria used by the PCT were unlawful because it contained no guidance regarding the primary health need approach which defined the limits of a local authority's responsibility to provide healthcare. This meant that there was the possibility of confusion around what test should be applied by the decision-makers when deciding upon the eligibility of an individual. The judgment also found the Department of Health's guidance on the primary health need approach to lack clarity.

The judgement also gave way to the term dubbed 'Grogan gap' in which it is possible for individuals to fall between health and social care provision. Strategic Health Authorities and Primary Care Trusts were instructed to review their criteria to ensure that this scenario would not happen and that treatment or care was not delayed by uncertainty over funding responsibilities.

In March 2006, the Department of Health responded to the Grogan judgment by publishing interim guidelines for Strategic Health Authorities (SHAs), PCTs and local authorities to follow until the National Framework was introduced on 1st October 2007.

THE PEARCE CASE, 2007

Mike Pearce was forced to sell the family home to fund his mother's care fees after she was deemed ineligible for continuing healthcare. His mother suffered with Alzheimer's disease and required full assistance with all activities of daily living. After a 5-year battle with Torbay PCT resulting in one of the first continuing healthcare assessments using the new National Framework (at the time not finalised), the Ombudsman upheld his complaint and recommended Torbay PCT pay £50,000 in retrospective restitution.

All the above cases examined individual needs and concluded that they were beyond being social care needs, i.e. they were above the local authority limits – and must therefore be viewed as health needs, which meant eligibility for NHS Continuing Healthcare funding.

This principle of local authority limits is made very clear in both the NHS Continuing Healthcare National Framework guidelines and also in the 'User notes' of the Decision Support Tool (DST) form (used in the full multidisciplinary team (MDT) assessment for NHS Continuing Healthcare). It is a statutory requirement for assessors and decision makers to consider local authority limits in every assessment for Continuing Healthcare funding.

It's incorrect for CHC assessors to deem that care provided by a spouse cannot be nursing care. In CHC it's irrelevant who provides the care; it's the nature of the care needs that matters.

Section 5 - Some Common Questions

Is there any diagnosis or prognosis that guarantees an automatic right to NHS Continuing Healthcare?

No. Eligibility for NHS Continuing Healthcare is based on needs and how those needs should be met, not any specific diagnosis. As such, until the assessment process has taken place, nobody can decide whether an individual will be eligible or not (including someone's GP)

Will a diagnosis of dementia increase the chances of eligibility?

It will depend on the progression of the illness and whether health and social care needs are assessed as being intense, complex and/or unpredictable. In such cases where the primary need is for health care, then they should be eligible.

Is there an authoritative definition of "beyond the responsibility of the local authority"?

There is a legal upper limit to the nursing and healthcare that can be provided by local authorities. This is a complex area of law and there is no simple authoritative definition of what is beyond the responsibility of the local authority. The powers and duties of local authorities are a matter of Statute and case law, including the Coughlan Judgment.

What role do financial considerations have in the decision-making process regarding NHS CHC eligibility and the subsequent commissioning and care planning processes?

The Framework makes clear that finance should not be a consideration in deciding eligibility for continuing healthcare. The Framework (para 82) states 'because the final eligibility decision should be independent of budgetary constraints, finance officers should not be part of a decision-making panel.,

Does the Framework apply retrospectively? Should it be used in retrospective review cases?

The original National Framework applied from 1st October 2007, and updated Frameworks applied from 1st October 2009 and 1st April 2013. Paragraph 145 of the 2009 National Framework reminds PCTs that when they are reviewing decisions made before 1st October 2007 they should apply the most relevant, lawful criteria for the period under consideration. However their decision should still comply with the Coughlan and Grogan judgments (see National Framework). The same approach should be taken by Independent Review Panels (IRPs)

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

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

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

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

If NHS CHC funding is granted, does this affect other benefits?

Some benefits will be affected when someone becomes eligible for NHS CHC. Receiving continuing healthcare whilst still living in their own home does not affect any social security benefits that they may be entitled to. In particular, those care/mobility benefits that are lost when in an NHS hospital can continue to be claimed.

If continuing healthcare funding is awarded to an individual who is a permanent resident of a Residential Care or Nursing Home, entitlement to social security benefits will be affected. For example the care component, mobility component and Attendance Allowance of the Disability Living Allowance would no longer be payable.

What happens if the individual being assessed has any communication needs and how should these be addressed?

The National Framework states (page 55)…' CCGs should consider the most likely communication needs to arise in the course of assessing for NHS continuing healthcare and make ongoing arrangements for appropriate support to be readily accessible. This could be, for example, by having arrangements with identified formal interpreters to be available at short notice. Preferred methods of communication should be checked with the person or their relatives, friends or representatives in advance. Where a person has specific communication needs such that it takes them longer than most people to express their views, this should be planned into the time allocated to carry out their assessment'

Does NHS-funded Nursing Care cover the entire cost of an individual's nursing needs?

No, it covers a contribution towards the cost of services provided by a registered nurse, involving either the provision of care or the planning, supervision or delegation of the provision of care, but it does not cover services which do not need to be provided or supervised by a registered nurse.

Section 6 - Further Information, Key Guidance Documentation and useful Organisations

Department of Health – key documents

1. The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care *November 2012 (Revised)*
2. What is NHS Continuing Healthcare? Easy Read.
3. NHS Continuing Healthcare Checklist *November 2012 (Revised)*
4. Decision-Support Tool for NHS Continuing Healthcare *November 2012 (Revised)*
5. Fast Track Pathway Tool for NHS Continuing Healthcare *November 2012 (Revised)*
6. NHS-Funded Nursing Care: Practice Guide *July 2013 (Revised)*
7. The NHS Continuing Healthcare (Responsibilities of Social services Authorities) Directions 2013
8. The Delayed Discharge (Continuing Care) Directions 2013

1 to 8 above are available at:

https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care

NHS Continuing Healthcare and NHS-funded Nursing Care Public Information Leaflet available at:

https://www.gov.uk/government/publications/nhs-continuing-healthcare-and-nhs-funded-nursing-care-public-information-leaflet

Equality Analysis - The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care *November 2012 (Revised)*

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/211257/Equality_Analysis.pdf

Age UK

A national charity that provides online information in respect of NHS CHC

http://www.ageuk.org.uk/health-wellbeing/doctors-hospitals/nhs-continuing-healthcare-and-nhs-funded-nursing-care/nhs-continuing-healthcare/

Age UK Factsheet 20 - NHS continuing healthcare and NHS-funded nursing care *(November 2016)*

http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/FS20_NHS_continuing_healthcare_and_NHS-funded_nursing_care_fcs.pdf?epslanguage=en-GB?dtrk=true

Beacon

www.beaconchc.co.uk

Telephone 0345 548 0300

A UK-wide social enterprise not for profit organisation that provides 'fair, in-depth and independent advice about every aspect of the NHS CHC process and criteria'. Beacon have been commissioned by NHS England to set up a support service for people in England who need free information and advice in relation to NHS CHC. At the time of writing, a free verbal (or written) advice session is available for up to 90 minutes.

Continuing Healthcare Alliance

Information on The Continuing Healthcare Alliance – a group of charities and organisations who believe that NHS continuing healthcare needs to be improved

https://www.parkinsons.org.uk/continuing-healthcare

Independent Age

A national charity that provides online information in respect of NHS CHC

https://www.independentage.org/information/advice-guides-factsheets-leaflets/continuing-healthcare-should-the-nhs-be-paying-for-your-care

Legislation

Part 6 of National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012 available at:

http://www.legislation.gov.uk/uksi/2012/2996/contents/made

Money Advice Service

Information on eligibility for NHS CHC via The Money Advice Service

https://www.moneyadviceservice.org.uk/en/articles/are-you-eligible-for-nhs-continuing-care-funding

NHS England

NHS Continuing Healthcare – Guide for Health and Social Care practitioners *(September 2014)*

https://www.england.nhs.uk/wp-content/uploads/2015/04/guide-hlth-socl-care-practnrs.pdf

NHS Continuing Healthcare – Quick reference guide to the National Framework *(September 2014)*

https://www.england.nhs.uk/wp-content/uploads/2015/04/qck-ref-guid-chc-nat-framwrk.pdf

NHS CHC Refreshed Redress Guidance

https://www.england.nhs.uk/wp-content/uploads/2015/04/nhs-cont-hlthcr-rdress-guid-fin.pdf

NHS England Operating Model for NHS Continuing Healthcare *Published 31 March 2015*

https://www.england.nhs.uk/wp-content/uploads/2015/03/ops-model-cont-hlthcr.pdf

(this document provides internal guidance for NHS staff and sets out the strategic importance for NHS CHC and the arrangements for NHS England to be assured of compliance with the National Framework)

NHS Choices

www.nhs.uk/ NHS Choices

Provides web based information on NHS structures, services, health conditions and healthy living.

Office of the Public Guardian (England & Wales)

www.gov.uk/browse/births-deaths-marriages/lasting-power-attorney

Telephone 0300 456 0300

The Office of the Public Guardian supports and promotes decision making for those who lack capacity or would like to plan for their future under the Mental Capacity Act 2005.

Parliamentary and Health Service Ombudsman

www.ombudsman.org.uk

Telephone 0345 015 4033

The Parliamentary and Health Service Ombudsman (PHSO) can investigate complaints about NHS care or services if you remain dissatisfied following a local investigation of your complaint. The PHSO may be approached if you remain dissatisfied following an IRP decision about NHS CHC eligibility.

Glossary of Terms

Anyone looking at eligibility for NHS CHC should familiarise themselves with the technical terms and jargon surrounding it These terms are used frequently throughout this document, and you will come across them frequently during any assessment process. Knowing what they mean will allow you to be involved in discussions and influence and understand the decisions that relate to a particular case.

Care Needs Portrayal

A care needs portrayal is a document that a multi-disciplinary team (see below) can complete when carrying out an assessment for NHS continuing healthcare. It records an individual's care needs and should be used as well as, rather than instead of, the Decision Support Tool (see below).

Checklist and Checklist Screening

The NHS continuing healthcare checklist (revised November 2012) is a 'light touch assessment' document that is used to help identify people who may qualify for NHS continuing healthcare assessment and who should then receive a full assessment (a process known as 'screening').

Clinical Commissioning Group (CCG)

A clinical commissioning group is a local NHS body that is responsible for providing services in a particular area. It is responsible for carrying out assessments and making decisions about NHS continuing healthcare, as well as for providing the care if it is awarded.

Commissioning Support Units (CSU)

CSUs provide services to a range of customers including CCGs, NHS England and Local Authorities. These support transformational change as well as transactional support such as IT, HR and business intelligence. Originally governed by NHS England, CSUs became autonomous organisations in 2016.

Continuing care

A general term describing care provided over a period of time to meet physical, mental health and personal care needs arising as a result of a disability, accident or illness

The Decision Support Tool (DST)

The Decision support tool for NHS continuing healthcare (revised November 2012) helps to bring together and record evidence of an individual's care needs in one document. It is used by the assessor during a full assessment, and helps to inform their decision about whether an individual is eligible for NHS continuing healthcare.

Discharge to Assess

"Discharge to assess" (also referred to as 'home first' or 'safely home') is designed to provide short term, funded support while the individual who doesn't require an acute hospital bed is discharged to their own home (where appropriate) or another community setting. Assessment for longer-term care and support needs is then undertaken in the most appropriate setting and at the right time for that individual.

Fast-track Pathway Tool

The Fast-track pathway tool for NHS continuing healthcare (revised November 2012) is the assessment tool for determining whether someone is eligible to be fast tracked to receive NHS continuing healthcare when they are near the end of their life.

The Framework

The National framework for continuing healthcare and NHS-funded nursing care (revised November 2012), which includes the NHS continuing healthcare practice guidance, is a long document produced by the NHS. It describes the processes that all NHS agencies must follow when carrying out NHS continuing healthcare assessments.

Independent Review Panel (IRP)

An independent review panel is a body that can be set up to assess whether a CCG has followed the correct procedures when assessing someone for NHS continuing healthcare. The IRP will tell the CCG of its decision, and the CCG should follow this.

Multidisciplinary team (MDT)

This is the team of people that carries out a full assessment for NHS continuing healthcare. It must consist of at least two professionals from different healthcare professions (such as GP, consultant or community mental health nurse) or one healthcare professional and one social care professional who is qualified in assessing people for care services. Other health and social care professionals involved in the individual's care should also be included, where possible.

NHS England

NHS England is the national body that runs the NHS in England. It oversees local services, such as hospitals and GP practices, and it is also responsible for setting up independent review panels. NHS England was formally established as the NHS Commissioning Board in October 2012.

NHS-Funded Nursing Care

Is care provided by a registered nurse for people who live in a care home. The NHS will pay a flat rate contribution directly to the care home towards the cost of this registered nursing care.

Nursing home

A nursing home provides personal care, much like a residential care home (see below), but also has a registered nurse on duty 24 hours a day. Some homes that are registered for nursing care will accept people with personal care needs who are expected to require nursing care in the future.

Primary Care Trust (PCT)

Primary care trusts (PCTs) were the statutory bodies in England responsible for ensuring NHS services were available in a defined geographical area and for improving the health of people living in that area (a role referred to as 'commissioning'). From April 2013 PCTs were replaced by Clinical Commissioning Groups (CCGs).

Practice Guidance

The NHS continuing healthcare practice guidance is part of the Framework (see above). It is produced to support practitioners and others who implement NHS continuing healthcare to carry out their role correctly.

Primary Health Need

A 'primary health need' is a key term that the Department of Health uses when it is deciding who is eligible for NHS continuing healthcare. If an individual's needs are for healthcare, as opposed to social care, then they are said to have a primary health need and they should receive NHS continuing healthcare funding.

Residential Care Home

A residential care home provides help with personal care such as washing, dressing and eating. In some residential care homes staff have had specialist training in dementia care.