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By Tom Powell

NHS continuing healthcare in England

Summary

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Contents

Summary

NHS continuing healthcare (CHC) is a package of health and social care arranged and funded solely by the NHS to meet physical and/or mental health needs arising from disability, accident or illness. Eligibility decisions for CHC rest on whether someone's need for care is primarily due to their health needs. For example, people who are eligible may have long-term complex medical conditions requiring highly specialised support.

In 2021/22, 104,400 people in England received NHS continuing healthcare (CHC). Around 61% of these were Fast Track cases, the pathway for those whose situation is deteriorating quickly.

This briefing is intended to help Members of Parliament respond to queries from constituents about eligibility for CHC in England. Equivalent provision in Scotland, Wales, and Northern Ireland is covered in the section 6.

Services provided by the NHS are free at the point of use, whereas those arranged by local authority social services are means tested. The outcome of any decision as to who has responsibility for providing care can have significant financial consequences for the individual concerned. A separate Library briefing Paying for adult social care in England, is designed to help answer constituents' queries about the local authority means-test for care home charges.

Integrated Care Boards (which replaced Clinical Commissioning Groups in July 2022) are responsible for commissioning CHC in England, although NHS England also has commissioning responsibilities for some specified groups of people (for example, prisoners and military personnel).

National Framework for NHS continuing healthcare

In 2007 the Department of Health issued a National Framework for NHS continuing healthcare. This Framework intends to improve the consistency of approach taken by local NHS bodies by providing a common framework for decision making and dispute resolution. The latest version of this Framework was published in May 2022.

This paper provides a summary of the key areas within the National Framework and other Department of Health and Social Care guidance. The official guidance should be consulted for a fuller account of the rules and

duties applying to NHS bodies responsible for determining eligibility for NHS CHC.

Legislation and the respective responsibilities of the NHS, social care and other services are different in child and adult services. For children and young people, from birth to their 18th birthday, needs are assessed against a children's national framework, with a recommendation made to a multi-agency panel (see Gov.uk, Children and young people's continuing care national framework, 2016).

Changes during the Covid-19 pandemic

Section 14 of the Coronavirus Act 2020 provided for NHS providers to delay undertaking the assessment process for CHC during the coronavirus pandemic.

The Government said the changes would enable patients to be discharged more quickly, when clinically appropriate, to free up hospital space for those who were very ill and enable clinicians to focus on delivering care. The Impact Assessment for the Bill said that NHS CHC assessments could cause delays to hospital discharge and require significant input from both NHS and local authority employees.

The CHC assessment processes were restarted from 1 September 2020 and revised Discharge to Assess arrangements were put in place. Details on the new process were provided in Department for Health and Social Care's guidance: Reintroduction of NHS continuing healthcare: guidance (August 2020). This guidance was withdrawn on 19 November 2021. The Government said all deferred assessments had been completed. This guidance is now for reference only.

Further reading

A separate Library paper on paying for adult social care in England is designed to help answer constituents' queries about the local authority means-test for care home charges

1 What is NHS continuing healthcare?

In England, NHS continuing healthcare (CHC) is a package of ongoing care provided outside hospital, arranged and funded solely by the NHS, where it has been assessed that an individual has a 'primary health need'.

Where a person is eligible for NHS CHC the NHS is responsible for providing all that individual's assessed health and associated social care needs, including accommodation, if that is part of the overall need. Services may be provided in any setting including, but not limited to, a residential care home, nursing home, hospice or a person's own home. If provided in a care home, it means the NHS also makes a contract with the care home and pays the full fees for the person's accommodation, board and care.

NHS funded nursing care is when the NHS pays for the nursing care component of care home fees (where care is provided by a registered nurse in a care home for someone not otherwise funded by the NHS – previously known as the Registered Nursing Care Contribution). In all cases individuals should be considered for eligibility for CHC before a decision is reached about the need for NHS-funded nursing care.

1.1 What legislation sets out continuing healthcare?

Primary legislation governing the health service does not explicitly define the duty of the NHS to provide continuing healthcare. It is from the broader requirements to provide a health service under the NHS Act 2006 (as amended) that the duty is derived. For example, section 3 of the 2006 NHS Act requires Integrated Care Boards (and previously Clinical Commissioning Groups) to provide a range of services, to such an extent as they consider necessary to meet all reasonable requirements. These services must include, amongst other categories:

> ...such other services or facilities for the prevention of illness, the care of persons suffering from illness, and the after-care of persons who have suffered from illness as the group considers are appropriate as part of the health service.[1]

[1] Section 3 (1)(e) of the NHS Act 2006

The duties of NHS bodies in relation to CHC and NHS-funded nursing care are laid down in Standing Rules.[2]

1.2 Who is eligible for continuing healthcare?

Eligibility for CHC care is not based on having a specific medical condition and eligibility places no limits on the settings where the package of support can be offered or on the type of service delivery.[3] The actual services provided as part of a CHC package should be tailored to meet the specific needs of the individual and should be seen in the wider context of best practice and service development for each "client group".

There is thus no specific set of services that must constitute 'continuing healthcare'. Services will depend on the needs of the individual in question and, whatever the services may be, people in receipt of CHC continue to be entitled, like other people, to the usual range of NHS primary, community, and secondary care, and any other NHS services.

An individual who has a package of support provided or funded by both the NHS and the local authority has what is known as a "joint package" of care.[4] Local authority social services have duties to provide welfare services, for example, and residential accommodation "for people who, by reason of age, illness or disability, are in need of care and attention that is not otherwise available to them."[5]

How the division of responsibility between the NHS and local social services is determined can have major repercussions for the respective expenditure of the NHS and the local social services authority. For individual patients it can mean the difference between a service that is provided for free (if it is the responsibility of the NHS) and one that is means-tested (if it is the responsibility of the local authority).

A separate Library note on Paying for adult social care in England is designed to help answer constituents' queries about the local authority means-test for care home charges.

2 The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012 (as amended); paragraphs 33 to 48 of the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care (2022) provide further information on the legal framework for CHC.

3 DHSC, National Framework (2022), page 7

4 As above, para 19

5 The basic role of the local authority is set out in paras 25-30, and the legal framework governing the role of local authorities is set out in paras 42-48 of The National Framework (2022).

2 NHS continuing healthcare statistics

2.1 Number of people receiving continuing healthcare

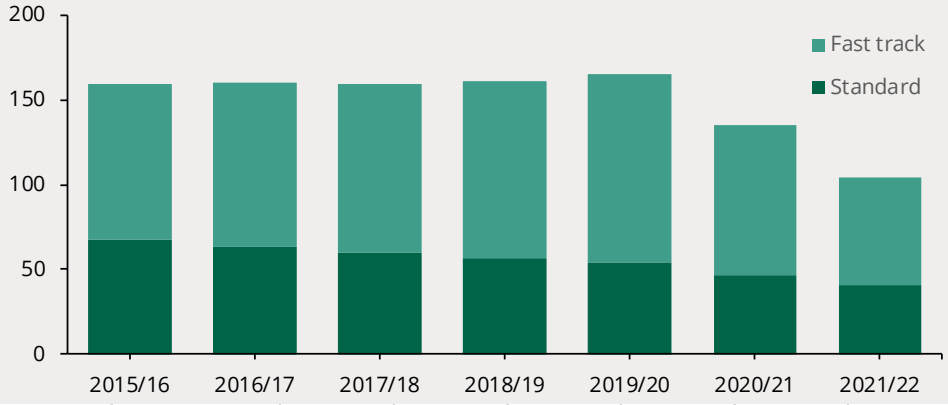
A total of 104,400 people in England received NHS CHC in 2021/22: of which around 61% were Fast Track cases, the pathway for those whose situation is deteriorating quickly.[6]

Annual numbers averaged around 160,000 between 2015/16 and 2019/20. The number fell in 2020/21 due to the suspension of CHC assessment work between April and August 2020 because of the coronavirus pandemic.[7]

Referrals have since increased but are yet to return to pre-pandemic levels. In addition, the approval rate for referrals was relatively low in the latter part of 2021/22. The combined effect of these factors contributed to the relatively low level of recipients in 2021/22.

Total numbers eligible for NHS CHC per year

England: Figures in thousands



Source: NHS England NHS Continuing Healthcare statistics

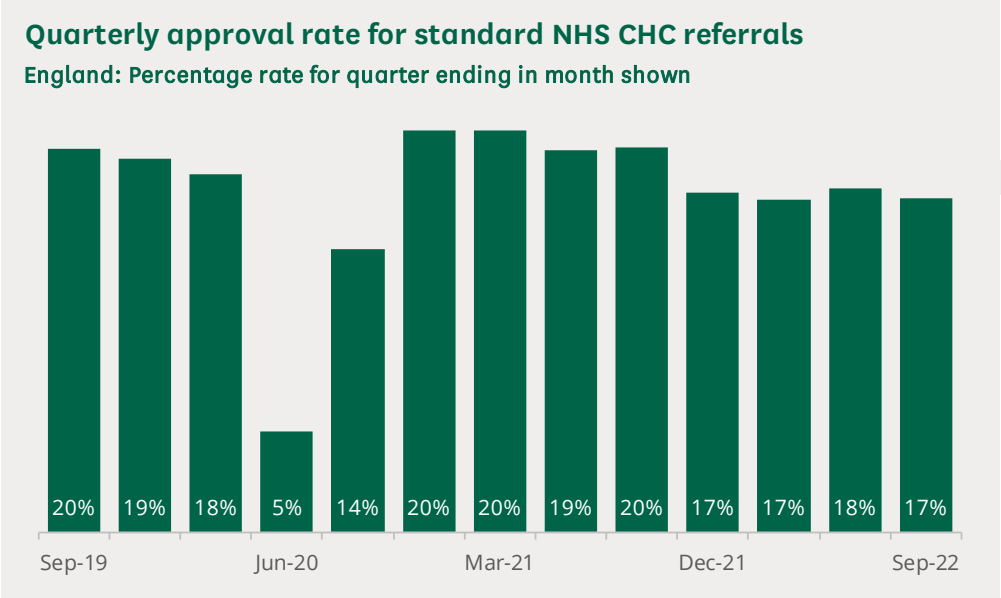
6 NHS England NHS Continuing Healthcare statistics

7 DHSC, Reintroduction of NHS continuing healthcare: guidance, 21 August 2020

2.2 Approvals data

The approval rate for individuals who are referred for a continuing healthcare checklist fell in quarters ending June 2020 and September 2020 as CHC assessments were largely suspended from April to August 2020.[8]

The approval rate then returned to around 20% throughout late 2020 and most of 2021. In the quarter ending December 2021, the proportion of referrals which were approved fell to 17% and has remained around this level since.



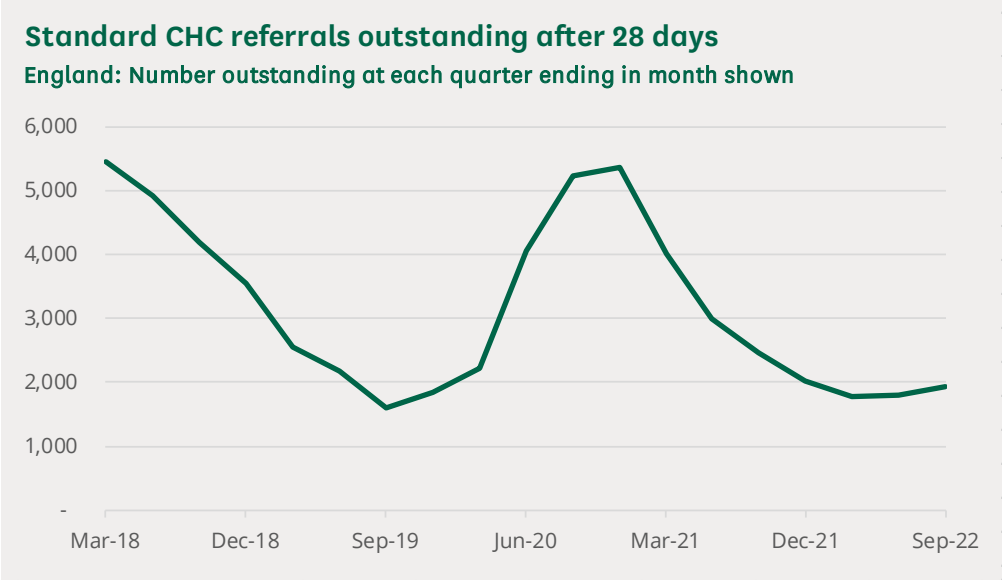
Source: NHS England NHS Continuing Healthcare statistics

Fast Track assessment rates have averaged 96% since the quarter ending March 2021.

2.3 Timeliness of referrals

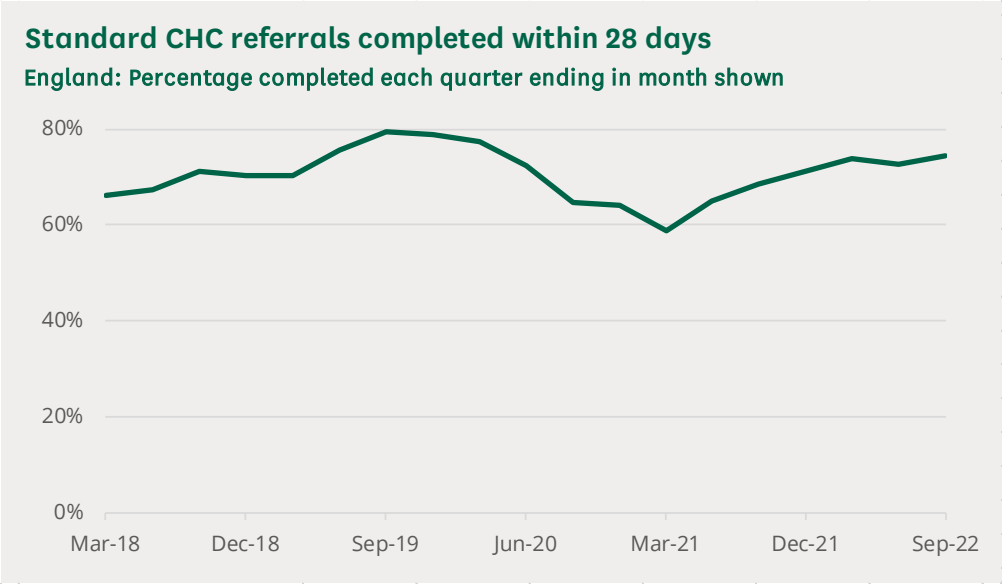
The number of CHC referrals outstanding after 28 days increased from September 2019 onwards, reaching a peak of around 5,350 cases in the quarter ending December 2020. Since then, numbers have fallen and in the quarter ending September 2022 there were 1,774 incomplete referrals exceeding 28 days.

[8] DHSC, Reintroduction of NHS continuing healthcare: guidance, 21 August 2020



Source: NHS England NHS Continuing Healthcare statistics

In terms of the proportion of standard CHC referrals resolved within 28 days, 74% were resolved within 28 days in the quarter ending September 2022. Prior to the suspension of CHC from April to August 2020[9], around 80% of referral were completed within 28 days.



Source: NHS England NHS Continuing Healthcare statistics

9 DHSC, Reintroduction of NHS continuing healthcare: guidance, 21 August 2020

3 The National Framework

3.1 Background

Following concerns about the local criteria used for making decisions about eligibility for CHC, and challenges to the legality of individual eligibility decisions in the courts, a national framework was published in June 2007. The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care (the National Framework) became mandatory from 1 October 2007.[10] Instead of different areas of England having their own rules for determining eligibility, the National Framework introduced a national approach for the NHS in England, with a common process and national tools to support decision making.[11] The Secretary of State issued regulations requiring NHS bodies and local authorities to comply with key aspects of the new policy.

The National Framework was substantially revised in November 2012 and incorporated the previously separate Practice Guidance, Frequently Asked Questions (FAQs) and Refunds Guidance.

The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012, set out NHS duties in this area. Regulations 21 (12) says in carrying out duties, NHS commissioning bodies must have regard to the National Framework. This means they are under a legal obligation to follow the Framework unless they have a good reason not to. The version of the Framework published in May 2022 makes clear that Integrated Care Boards, which replaced Clinical Commissioning Groups (CCGs) in July 2022, must similarly have regard to the 2012 regulations.

3.2 The primary health need test

The central criterion for receipt of CHC is whether a person's primary need is a health need.[12] In order to determine whether an individual has a primary health need, an assessment of eligibility process must be undertaken by a

[10] The revised version of the National Framework, published in May 2022, came into force in July 2022, and was updated in October 2022. Previous versions are also available for 2012, 2009 and 2007; See also Written Ministerial Statement HC Deb 26 June 2007 20-21WS; Department of Health Press Notice, "Streamlining the system for NHS continuing care", dated 26 June 2007, is no longer available online.

[11] See the final page of this Briefing Paper for a list of associated guidance documents.

[12] DHSC, National Framework (2022)

multidisciplinary team. The National Framework states that determining whether an individual has a primary health need involves looking at the "totality" of their relevant needs.[13]

The National Framework says an individual has a primary health need if the main aspects or majority part of the care they require is focused on addressing and/or preventing health needs. The Framework adds that a primary health need is about a person's everyday care needs:

> having a primary health need is not about the reason why an individual requires care or support, nor is it based on their diagnosis; it is about the level and type of their overall actual day-to-day care needs taken in their totality.[14]

The Framework says people should not find themselves in a situation where the NHS nor the relevant local authority will fund their care, either separately or together.[15]

Therefore, the 'primary health need' test should be applied, so that a decision of ineligibility for CHC is only possible where, taken as a whole, the nursing or other health services required by the individual:

> a) are no more than incidental or ancillary to the provision of accommodation which local authority social services are, or would be but for a person's means, under a duty to provide; and
>
> b) are not of a nature beyond which a local authority whose primary responsibility it is to provide social services could be expected to provide.[16]

The definition of what a local social services authority might provide was established in the Coughlan judgment of 1999.[17] The National Framework summarises one of the key points from the judgment as follows:

> No precise legal line can be drawn between those nursing services that can be provided by a Local Authority and those that cannot: the distinction between those services that can and cannot be provided by a Local Authority is one of degree, and will depend on a careful appraisal of the facts of an individual case.[18]

Characteristics of need

Certain characteristics of need – and their impact on the care required to manage them – are used to help determine whether the 'quality' or 'quantity' of health services required are beyond the limits of a local authority's

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13 DHSC, National Framework (2022), para 55

14 As above, para 56

15 Subject to the person's means, and the person having needs that fall within the eligibility criteria for care and support.

16 DHSC, National Framework (2022), para 59

17 The significance and impact of the *Coughlan* judgement is explained in Annex B of the National Framework and in a separate Library briefing, Background to the National Framework for NHS Continuing Healthcare (SN04643).

18 DHSC, National Framework (2022), Appendix B, paragraph 3.

responsibilities. These characteristics are listed in the National Framework as:

> **Nature:** This describes the particular characteristics of an individual's needs (which can include physical, mental health or psychological needs) and the type of those needs. This also describes the overall effect of those needs on the individual, including the type ('quality') of interventions required to manage them.
>
> **Intensity:** This relates both to the extent ('quantity') and severity ('degree') of the needs and to the support required to meet them, including the need for sustained/ongoing care ('continuity').
>
> **Complexity:** This is concerned with how the needs present and interact to increase the skill required to monitor the symptoms, treat the condition(s) and/ or manage the care. This may arise with a single condition, or it could include the presence of multiple conditions or the interaction between two or more conditions. It may also include situations where an individual's response to their own condition has an impact on their overall needs, such as where a physical health need results in the individual developing a mental health need.
>
> **Unpredictability:** This describes the degree to which needs fluctuate and thereby create challenges in managing them. It also relates to the level of risk to the person's health if adequate and timely care is not provided. Someone with an unpredictable healthcare need is likely to have either a fluctuating, unstable or rapidly deteriorating condition.[19]

Each of these characteristics may, alone or in combination, demonstrate a primary health need. In addition, the Framework says the possibility of deterioration should also be taken into account. Where an individual has a rapidly deteriorating condition that may be entering a terminal phase, this may constitute a primary health need because of the rate of deterioration. The Department of Health and Social Care has published a Fast Track Pathway Tool to help decide eligibility where this may be the case.[20] In order to minimise variation in the interpretation of these factors, the Department also published a Decision Support Tool. Further information about the Decision Support Tool and the Fast Track Tool is outlined in section 3.3 of this briefing.

As well as describing the characteristics on which eligibility should be based, the Framework includes a section on what eligibility should **not** be based on. It lists the following examples:

- the person's diagnosis;
- the setting of care;
- the ability of the care provider to manage care;
- the use (or not) of NHS-employed staff to provide care;

19 DHSC, National Framework (2022), para 60

20 As above, paras 240-269

- the need for/presence of 'specialist staff' in care delivery;
- the fact that a need is well managed;
- the existence of other NHS-funded care; or
- any other input-related (rather than needs-related) rationale.[21]

3.3 Getting an assessment

The NHS should carry out an assessment for CHC if it seems someone may need it. The charity, Age UK, notes some of the situations when NHS staff or a member of the social work team should consider whether an assessment should be carried out, including:

- if staff believe, after a period of rehabilitation following a hospital stay, that a patient's condition is unlikely to improve;
- before deciding they need NHS-funded nursing care in a nursing home;
- when health or social care needs are being reviewed as part of a community care assessment;
- if physical or mental health deteriorates significantly and current levels of care seems inadequate;
- when nursing needs are being reviewed; this should happen annually for those living in a nursing home; or
- if an individual has a rapidly deteriorating condition and may be approaching the end of life.[22]

Carers and family can also ask for an assessment for the person they look after by talking to a health or social care professional working with them or the Integrated Care Board. In most cases what is known as the NHS continuing care checklist would be used to carry out an initial assessment to decide if an individual needs to be referred for a full assessment. However, if someone needs care urgently, for example because they are terminally ill, they should be assessed under the Fast Track Pathway Tool.

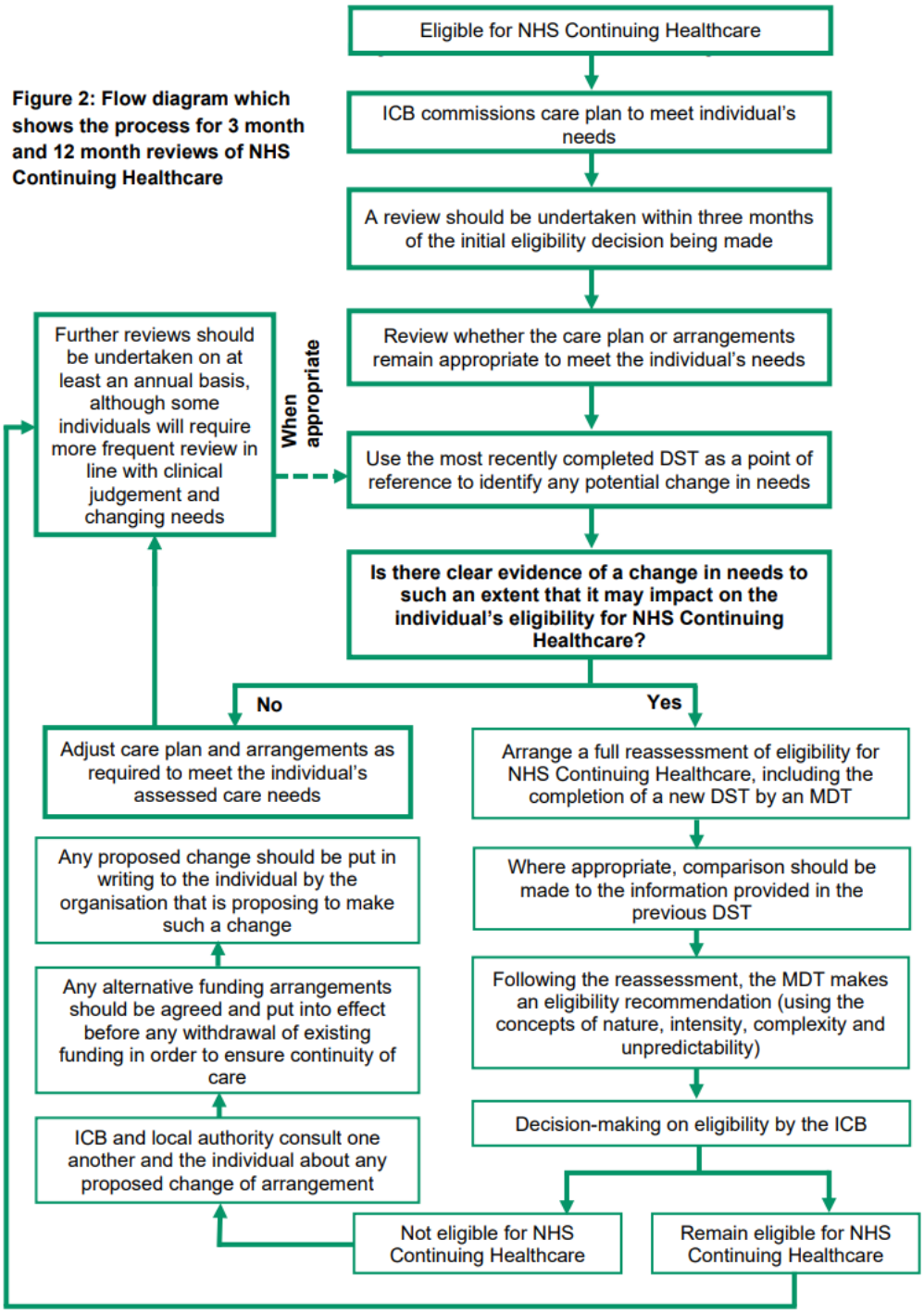
The National Framework sets out principles and values that should be applied to the process of assessment, for example, obtaining the patient's consent, what happens when the patient does not have capacity to consent, and making patients aware of advocacy services that might be available. The Framework then describes the process of establishing eligibility.

21 DHSC, National Framework (2022), para 66

22 Age UK, NHS continuing healthcare

This diagram, from the National Framework, summarises the assessment and review process for CHC:

Figure 2: Flow diagram which shows the process for 3 month and 12 month reviews of NHS Continuing Healthcare



Source: DHSC, National Framework (2022), fig. 2

Where a patient is receiving CHC a case review should be undertaken no later than three months after the initial eligibility decision, to reassess care needs and eligibility, and to ensure their needs are being met. Reviews should then

take place annually, as a minimum.[23] These reviews are separate from the dispute resolution reviews described in section 4 of this briefing.

Initial checklist

The first step for most people is a screening process where a nurse, doctor, qualified healthcare professional or social worker applies a Checklist to see if the individual needs a full assessment of eligibility. Whatever the outcome of the Checklist process, the decision, including the reasons why the decision was reached, should be communicated clearly and in writing to the individual and (where appropriate) their representative.

Where the outcome is not to proceed to a full assessment of eligibility, the written decision should also contain details of the individual's right to ask the Integrated Care Board (ICB) to reconsider the decision. The ICB should give such requests due consideration and provide a clear, written response as soon as is reasonably practicable. The response should also give details of the individual's rights under the NHS complaints procedure.[24]

Full Assessment and the Decision Support Tool

Full assessments should be carried out by a multidisciplinary team (MDT) made up of a minimum of 2 professionals from different healthcare professions. The NHS website states the MDT should usually include both health and social care professionals who are already involved in the patient's care.[25]

The aim is to capture the nature, complexity, intensity and/or unpredictability of a person's needs (see section 3.2 on the primary health need test above). In order to do this, the Decision Support Tool (DST) provides a framework for recording the person's needs in 12 generic areas. The 12 areas are:

- breathing
- nutrition
- continence
- skin integrity
- mobility
- communication
- psychological and emotional needs

23 DSHC, Public information leaflet: NHS continuing Healthcare and NHS-funded nursing care, August 2022

24 DSHC, National Framework (2022), para 133

25 NHS website, NHS continuing healthcare, reviewed 25 March 2021

- cognition
- behaviour
- drug therapies and medication
- altered states of consciousness and
- other significant care needs.[26]

Those carrying out the assessment should look at what help is needed, how complex these needs are, how intense and unpredictable these needs can be, as well as any risks that would exist if adequate care was not provided. For each of these issues a decision is then made about the level of need. The levels are marked "priority", "severe", "high", "moderate", "low" or "no needs".[27]

The NHS website states that individuals with at least one priority need, or severe needs in at least two areas, can usually expect to be eligible for CHC.[28]

Someone may also be eligible if they have a severe need in one area plus several other needs, or a number of high or moderate needs, depending on their nature, intensity, complexity or unpredictability.

The assessment should consider the views of the individual being assessed and the views of any carers. The professional(s) completing the checklist should record in writing the reasons for their decision and share this with the individual being assessed.[29]

Indicative guidelines as to thresholds are set out in the DST but these should not be viewed prescriptively. The DST is not an assessment in itself; it is meant to be a way of applying the primary health need test by bringing together evidence in a single format to improve consistency and evidenced-based decisions. It is not intended to directly determine eligibility and the Framework states that "professional judgment should be exercised in all cases to ensure that the individual's overall level of need is correctly determined."[30]

Once the multidisciplinary team has reached agreement, it should make a recommendation to the ICB on eligibility. The ICB will only reject the recommendation in exceptional circumstances and for clearly articulated reasons. A decision not to accept the recommendation should never be made by one person acting unilaterally.[31]

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26 DHSC, National Framework (2022), para 156

27 DSHC, NHS Continuity healthcare decision support tool, updated 27 October 2022, para 20

28 NHS website, NHS continuing healthcare, reviewed 25 March 2021

29 As above.

30 DSHC, National Framework (2022), para 161

31 As above, paras 173 and 176

The Framework says the ICB may choose to use a panel to ensure consistency and quality of decision making. The Framework also notes the panel should not fulfil a gate-keeping function nor should it be used as a financial monitor:

> The final eligibility decision should be independent of budgetary constraints, and finance officers should not be part of a decision-making process.[32]

The time between the Checklist (or other notification of potential eligibility) being received by the ICB and the funding decision should, in most cases, not exceed 28 days. In acute settings it may be appropriate for it to take much less than this. When there are valid and unavoidable reasons for the process taking longer, timescales should be clearly communicated to the person, and (where appropriate) their carers and/or representatives.[33]

Deteriorating conditions and the Fast Track Pathway Tool

The Fast Track Pathway Tool is designed for assessing individuals who need urgent attention because they have a rapidly deteriorating condition that may be entering a terminal phase with an increasing level of dependency. Ministers have emphasised that the use to the tool should not be restricted to situations where death is imminent:

- 'rapidly deteriorating' should not be interpreted narrowly as only meaning an anticipated specific or short time frame of life remaining; and
- 'may be entering a terminal phase' is not intended to be restrictive to only those situations where death is imminent.[34]

The Tool needs to be completed by an "appropriate clinician", who should give the reasons why the person meets the conditions required for the fast-tracking decision.[35] Where a recommendation is made for an urgent package of care via the fast-track process, it should be accepted and actioned immediately by the ICB. The Framework says it is not appropriate for individuals to experience delay in the delivery of their care package while disputes over the use of the Fast Track Pathway Tool are resolved.[36]

Further information on end of life care can be found on the NHS website, what end of life care involves. Dying matters is a coalition of organisations aiming to help people talk more openly about dying, death and bereavement, and to

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32 DSHC, National Framework (2022), para 176

33 As above, paras 182-184

34 PQ 1673 [on Continuing Care], 14 January 2020

35 DSHC, National Framework (2022), paras 241-7; The 'appropriate clinician' is defined as someone who is, pursuant to the NHS Act 2006, responsible for an individual's diagnosis, treatment or care and who are medical practitioners (such as consultants, registrars or GPs) or registered nurses. Clinicians should have an appropriate level of knowledge or experience of the type of health needs, so that they are able to comment reasonably on the situation. They can be clinicians employed in voluntary and independent sector organisations that have a specialist role in end of life needs (for example, hospices), provided that they are offering services pursuant to the NHS Act 2006.

36 DSHC, National Framework (2022), para 262

make plans for the end of life. It provides information about planning ahead. The charity, Compassion in Dying also provides information on end-of-life care.

3.4 Individual choice of care arrangement, personal health budgets and limits on choice

The National Framework says "the package to be provided is that which the ICB assesses is appropriate to meet all of the individual's assessed health and associated care and support needs."[37] It goes on to state that in doing so, the ICB should have due regard to the individual's wishes and preferred outcomes, and the approach taken should be in line with the principles of personalisation (set out in paragraphs 320-324 of the Framework).

The Government's public information leaflet on CHC explains the ICB "will discuss options with you as to how your care and support needs will be best provided for and managed" and that how and where a person wants to receive care will be considered:

> When deciding on how your needs will be met, your wishes and preferred outcomes should be taken into account. This should include discussions about your preferred setting in which to receive care (for example, at home or in a care home) as well as how your needs will be met and by who.[38]

Personal health budgets

People who are eligible for CHC have the right to ask for a Personal Health Budget (PHB), to provide more choice over the services and care they receive.

The NHS website states that a PHB allows individuals to manage their healthcare and support needs, such as treatments, equipment and personal care. It works in a similar way to personal budgets, which allow people to manage and pay for their social care needs.[39] PHBs are mainly aimed to support people arranging care in their own homes, and cannot be used to pay care home fees.

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37 DSHC, National Framework (2022), para 192

38 DSHC, Public information leaflet: NHS continuing Healthcare and NHS-funded nursing care, August 2022

39 NHS website, What is a personal health budget?, reviewed 28 October 2020

The NHS website explains that a PHB can be managed in three ways, or a combination of these:

> **1. Notional budget**
>
> No money changes hands. You find out how much money is available for your assessed needs and together with your NHS team you decide on how to spend that money. They will then arrange the agreed care and support for you.
>
> **2. Third party budget**
>
> An organisation legally independent of both you and the NHS (for example, an independent user trust or a voluntary organisation) holds the money for you, and also pays for and arranges the care and support agreed in your care plan
>
> **3. Direct payment for healthcare**
>
> You get the money to buy the care and support you and your NHS team agree you need. You must show what you have spent it on, but you, or your representative, buy and manage services yourself.[40]

NHS England has published further guidance on direct payments for healthcare.

PHBs were piloted for CHC from 2009. From October 2014, adults eligible for CHC have had the legal right to have a personal health budget.[41] The NHS can offer a PHB either as a notional budget or a real budget held by a third party. NHS England has said that unless there are exceptional circumstances, everyone living in their own home who is in receipt of CHC will have a personal health budget.[42]

At the time, the Government explained that the introduction of a "right to have" a PHB would provide continuity, removing the fear of losing control from those transitioning to CHC from direct payments in social care.

Ministers noted that despite the legal right to request a PHB, there would continue to be people for whom they were not appropriate for clinical or financial reasons.[43]

Limits on patient choice

The National Framework states that ICBs can take comparative costs and value for money into account when determining the model of support to be provided, putting limits on individual choice where this would result in the NHS paying for a more expensive care arrangement. The practice guidance

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40 NHS website, What is a personal health budget?, reviewed 28 October 2020

41 Department of Health press release, 5 October 2011; the National Health Service (Direct Payments) Regulations 2013 (SI 2013/1617), which came into force on 1 August 2013, enable the NHS across England to make direct payments for healthcare. Previously this was only possible in the approved pilot sites.

42 NHS England, Personal health budgets in NHS Continuing Healthcare, accessed 6 February 2023

43 HC Deb 8 October 2013, 16WS

notes that cost must be balanced against other factors in the individual case, such as an individual's desire to continue to live in a family environment.[44]

Higher cost care packages

The National Framework notes that funding provided by ICBs in CHC packages should be sufficient to meet the needs identified in the care plan, based on the ICB's knowledge of the costs of services for the relevant needs in the locality where they are to be provided.

If an individual expresses a preference for higher-cost accommodation, the ICB should also liaise with the individual to identify reasons for their preferences.[45]

There is guidance on situations where an individual becomes eligible for CHC whilst already resident in a care home for which the fees are higher than the NHS would usually meet. The guidance states that, in the first instance, the ICB should meet the patient and offer to review the care package in order to identify whether a different package would be more appropriate.[46]

There are some circumstances where an ICB may propose a move to different accommodation or a change in care provision. The guidelines state the ICB should consider the "frailty, mental health needs or other relevant needs of the individual" when determining an accommodation move.[47] A transition care plan should also be developed between the old and new providers.[48]

If an individual wishes to dispute a decision of the NHS not to pay for higher-cost accommodation, in the first instance they should do this via the NHS complaints process (see section 4 of this briefing).

Patients who wish to pay for additional care

The National Framework provides guidance for NHS patients who wish to pay for additional private care. For example, the Framework provides "hairdressing, aromatherapy, beauty treatments and entertainment services" as examples of additional private services which might be purchased separately.[49]

Supporting individuals eligible for NHS continuing healthcare in their own home

When remaining in their own home whilst being eligible for NHS continuing healthcare, costs such as equipment provision, laundry and daily domestic

44 DSHC, National Framework (2022), para 197 and PG 45
45 As above, para 304
46 As above, paras 303-314
47 As above, para 308
48 As above, para 312
49 As above, para 299

tasks may be met by the ICB if they are assessed health and associated social care need. Rent, food and normal utility bills are expected to be covered by personal income or welfare benefits.[50]

[50] DSHC, National Framework (2022), para 316

4 Dispute resolution

4.1 Reviews of NHS continuing healthcare decisions

The charity, Age UK set out what individuals can do if they receive a decision confirming they are not eligible for CHC

If it's decided someone is not eligible for NHS continuing healthcare, they can appeal the decision:

- The ICB letter explaining the decision should have information on how to appeal.
- If they are not happy with a Checklist decision they can ask the ICB to reconsider their case. If they are still dissatisfied, the NHS complaints system can be used to pursue the case.
- If the person is not happy after a full assessment, they can ask the ICB to reconsider its decision. If still dissatisfied, they can ask for an independent review of the case.[51]

Age UK also note other options, including requesting a local authority assessment for care, or check eligibility for NHS-funded nursing care.[52]

There are three possible levels at which a review of an eligibility decision (as distinct from an initial assessment) may take place:

1. A local review and resolution process run by the Integrated Care Board (ICB);
2. A request to NHS England for review by an Independent Review Panel (IRP);
3. If the Independent Review Panel upholds the original decision and there is still a challenge, the next stage is referral to the Health Service Ombudsman.

Following a decision on an individual's assessment of eligibility for NHS CHC using the Decision Support Tool, the ICB should notify the individual and/or

[51] Age UK, NHS continuing healthcare, updated 3 February 2023
[52] As above.

their representative of the right to request a review when sending the final decision letter.[53]

The National Framework states that each ICB must have a CHC local resolution process, including timescales, which should be publicly available. The process must also take account of the detailed guidelines in the Framework.[54]

Once local procedures have been exhausted, the case should be referred to an NHS England Independent Review Panel (IRP), which should consider the case and make a recommendation to the ICB. If using local processes would cause undue delay, NHS England has discretion to agree that the matter should proceed direct to an IRP without completion of the local process.[55]

The Framework says that because IRPs have a scrutiny and reviewing role, it is not necessary for any party to be legally represented at an IRP hearing although individuals may be represented by family, advocates, advice services and others in a similar role. It also says that although the role of the IRP is advisory, its recommendations should be accepted by the relevant ICB in all but exceptional circumstances. The Framework sets out principles to be followed both locally and by IRPs (such as in the gathering of available evidence). An individual's right under existing NHS complaints procedures and their existing right to refer a case to the Health Service Ombudsman is not affected by the IRP procedures.[56]

In November 2020 the Health Service Ombudsman published Continuing Healthcare: Getting it right first time, a report identifying failings in NHS CHC and making recommendations for improvements.

Disputes between the NHS and local authorities, and between ICBs

The National Framework states that a local multi-agency dispute resolution process should be in place in each local area, through which disputes between ICBs and local authorities relating to CHC can be managed.[57]

NHS England has also published guidance on determining which NHS commissioner is responsible for commissioning healthcare services and making payments to providers (also known as "Who Pays?"). This includes detailed guidance for ICBs on determining responsibility for CHC, out-of-area placements, and on transferring funding between ICBs if an eligible individual moves from one ICB area to another. In general terms, the guidance suggests

53 NHS England, NHS Continuing Healthcare, reviewed March 2021

54 DHSC, National Framework (2022), para 215

55 As above, para 217

56 As above, para 224. Annex D provides further details of procedures to be followed in relation to Independent Review Panels. There are also provisions regarding disputes between ICBs and local authorities about who is the responsible body to provide care (see paras 228-239 and Annex E).

57 As above, paras 228-236

the 'usual residence' of the individual concerned determines the responsibility of the ICB.

'Usual residence' is defined as where the individual is registered with a GP or, if they are not registered with a GP, the place where the individual is living. Annex 1 to the "Who Pays?" guidance provides information on procedures to follow if there is a dispute between ICBs.[58]

4.2 Refunds guidance

Annex E of the National Framework sets out the approaches to be taken by NHS England, ICBs and local authorities when a decision is awaited on eligibility for CHC or there is a dispute following a decision. It explains responsibilities for providing services during these periods and for refunding the costs of services provided.

The following paragraphs of Annex E set out guidance on refunds where an ICB's eligibility decision is revised as a result of an individual disputing a refusal to provide CHC (following further consideration or as a result of a recommendation by an Independent Review Panel), or when an "unreasonable delay" occurred when awaiting a decision:

> 12. Where unreasonable delay has occurred and it is an LA that has funded services during the interim period, the ICB should refund the local authority the costs of the care package that it has incurred during the period of unreasonable delay. The ICB can use its powers under section 256 of the NHS Act to make such payments. The amount to be refunded to the local authority should be based on the gross cost of the services provided. Where an individual has been required to make financial contributions to the local authority as a result of an assessment of their resources under the Care Act 2014, the above approach should be adopted rather than the ICB refunding such contributions directly to the individual as the refund of contributions is a matter between the local authority and the individual. Where an ICB makes a gross cost refund, the local authority should refund any financial contributions made to it by the individual in the light of the fact that it has been refunded on a gross basis, including interest.
>
> 13. Where an ICB has unreasonably delayed reaching its decision on eligibility for NHS Continuing Healthcare, and the individual has arranged and paid for services directly during the interim period, the ICB should make an ex-gratia payment in respect of the period of unreasonable delay.[59]

[58] NHS England, Who Pays? Determining which NHS commissioner is responsible for commissioning healthcare services and making payments to providers, 1 July 2022

[59] DHSC, National Framework (2022), Annex E 'Guidance on responsibilities when a decision…is awaited or disputed', paras 12 and 13

5 Continuing healthcare in other parts of the UK

5.1 Wales

In Wales, Continuing NHS Healthcare operates in a similar way to CHC in England. Welsh Health Boards are responsible for ensuring that Continuing NHS Healthcare is provided to individuals. The National Framework for Continuing NHS Healthcare sets out a mandatory process for the NHS in Wales, working together with local authorities, to assess health needs decide on eligibility, and to provide appropriate care for adults. The most recent vision of the Welsh National Framework was published in 2021 and updated in 2022 (the 2021 version replaced an earlier Framework from 2014).

Further background can be found in a 2019 Welsh Government consultation on the revised Framework, and a summary of responses were published in November 2019.[60] A Written Ministerial Statement to the Welsh Assembly announced the publication of the 2021 Framework.[61]

The charity, Age Cymru, have published a factsheet on NHS Continuing Healthcare and NHS-funded nursing care in Wales (PDF) (December 2022).

5.2 Scotland

In Scotland, NHS continuing healthcare was replaced by 'Hospital Based Complex Clinical Care' from 28 May 2015, which marked the Scottish Government's full acceptance of the Independent Review of NHS Continuing Healthcare.[62]

According to the Scottish Government's guidance (PDF), this may mean a longer stay in hospital for some patients, the main aim being to enable them to recover enough to return to "whatever setting is most suitable for them in

60 Welsh Government, Consultation: Continuing NHS Healthcare, 2019

61 Welsh Government, Written Statement: Publication of the NHS Continuing Healthcare (CHC) National Framework 2021 and Decision Support Tool and consideration of the interface between CHC and direct payments, 20 July 2021

62 Scottish Government, Independent Review of NHS Continuing Healthcare, May 2014

the community while ensuring that all health or social care needs are supported."[63]

Assessment for long-term complex clinical care will now be based around a single eligibility question: "Can the individual's care needs be properly met in any setting other than a hospital?" If, following a full assessment, the answer to this question is yes, then the person will be discharged from NHS care to a suitable community setting – home with support, a care home or supported accommodation. At this point the local authority's charging policies will apply, and the individual may have to contribute towards the cost of their care.[64]

Announcing this change on 2 May 2014, the then Cabinet Secretary for Health and Wellbeing, Alex Neil, said: "Where patients are assessed as needing this form of acute long-term care the expert group make clear that the most effective and safe way to deliver this is in a hospital setting."[65] This change was part of the integration of health and social care in Scotland starting from April 2015.

Care Information Scotland has a webpage on Hospital Based Complex Clinical Care.

5.3 Northern Ireland

Continuing healthcare is available in Northern Ireland, although health and social care is fully integrated: the Health and Social Care board (HSCB) is responsible for commissioning health and social care services for the local population and Health and Social Care Trusts (HSCT) are required to deliver services. The basic principles for assessing eligibility for Continuing Healthcare are set out in the Northern Ireland Circular HSC (ECCU) 1/2010 Care Management, Provision of Services and Charging Guidance, which says:

> ...it is for clinicians, together with other health and social care professional colleagues and in consultation with the service user, his/her family and carers to determine through a comprehensive assessment of need whether an individual's primary need is for healthcare or for personal social services. In the latter case, the service user may be required to pay a means tested contribution.[66]

HSC Trusts are responsible for ensuring that an assessment of need is carried out for individuals with a multi-disciplinary professional and with clinical input as required. The assessment process covers both health and social care needs and should focus on maximising opportunities for independent living. If

63 Scottish Government, Hospital Based Complex Clinical Care Guidance (PDF), May 2015,

64 As above, pp2-6

65 As above, p2

66 Northern Ireland Department of Health, Social Services and Public Safety, Care Management, Provision of Services and Charging Guidance, 11 March 2010, p5

the outcome of an assessment indicates a primary need for healthcare, then the HSC Trust is responsible for finding the complete package of care in any setting, which is referred to as continuing healthcare. If the outcome of an assessment indicates a primary need for social care, this need may be met in a residential or nursing home setting, where HSC Trusts are required to levy a means-tested charge.

If the assessment identifies that nursing home care is appropriate and that the individual is responsible for meeting the full costs of their nursing home care, then the relevant HSC Trust is responsible for making payment of £100 per week to cover the cost directly to the nursing home provider.[67]

The charity, Age NI, conducted a study of the provision of Continuing Healthcare in Northern Ireland, and presented their findings and recommendations in a report – The Denial of NHS Continuing Healthcare in Northern Ireland (May 2014). This argued that older people were being denied access to assessments for continuing healthcare, partly because of a lack of clear guidance. It recommended the Northern Ireland Department of Health "draft and publish guidance on NHS Continuing Healthcare in NI to provide clarity and to require collation and monitoring of data in a standardised way."[68]

In response to this, the Department carried out a comprehensive review before publishing a consultation document in 2017.[69]

This considered several potential options, including:

- Introducing a Continuing Healthcare Decision Support Tool Model
- Introducing a Single Eligibility Criteria Question
- Developing Standalone Guidance and assessment Checklist Specific to the HSC System in Northern Ireland.[70]

The Department consulted on the review between 19 June and 15 September 2017, and published an analysis of responses in February 2021.[71]

5.4 Patients who move across borders in the UK

NHS England guidance on determining which NHS commissioner is responsible for commissioning healthcare services and making payments to

67 Northern Ireland Department of Health, Continuing Healthcare Consultation- Consultation Document, 2017, p2
68 Age NI, The Denial of NHS Continuing Health in Northern Ireland, May 2014, p28.
69 Northern Ireland Department of Health, Continuing Healthcare in Northern Ireland: Introducing a Transparent and Fair System: Consultation Document, June 2017
70 As above, pages 6-11
71 Northern Ireland Department of Health webpage, Continuing Healthcare in Northern Ireland: Introducing a Transparent and Fair System, accessed 6 February 2023

providers, includes some guidance on the transfer of English CHC patients across borders within the UK:

> Where an English ICB arranges a cross-border package of residential continuing care (other than a package that is only NHS-funded nursing care) in Scotland, Wales or Northern Ireland, the "placing ICB" exception described in paragraph 14 applies and the ICB will remain responsible for commissioning and payment for that person's care package until that episode of care has ended. This is a reciprocal arrangement; in cases where people are assessed as eligible for CHC, and are placed by the Scottish, Welsh or Northern Irish health board in a care home in England, the placing health board will remain responsible for funding the care home placement.[72]

[72] NHS England, Who Pays? Determining which NHS commissioner is responsible for commissioning healthcare services and making payments to providers, June 2022, para 19.7

6 Guidance documents and further information

The following official guidance should be consulted for a fuller account of the rules and duties of NHS bodies in England to provide CHC.

- National framework for NHS continuing healthcare and NHS funded nursing care (revised October 2022): This sets out principles and processes for establishing eligibility.
- NHS continuing healthcare: checklist (October 2022): This is a screening tool to help establish who might need a full assessment of eligibility.
- Decision support tool for NHS continuing healthcare (October 2022): This is a detailed questionnaire to help assess eligibility.
- Fast track pathway tool for NHS continuing healthcare (August 2022): This is for urgent assessments of those with rapidly deteriorating, possibly terminal, conditions.
- NHS-funded nursing care best practice guidance (August 2022)

There are also several introductory sources that constituents may find useful. For example:

- Department of Health and Social Care Public Information Leaflet, NHS Continuing Healthcare and NHS Funded Nursing Care (August 2022)
- NHS website: NHS Continuing Healthcare (reviewed 25 March 2021)
- Age UK, Factsheet 20, NHS continuing healthcare and NHS-funded nursing care (PDF) (revised July 2022)
- Alzheimer's Society, When does the NHS pay for care? Guidance on eligibility for NHS continuing healthcare funding in England (PDF) (revised November 2022)

6.1 Where can constituent's get further support and advice?

As part of the CHC process, NHS England funds a social enterprise called Beacon, which can act as a patient's CHC adviser. NHS England's website on NHS CHC provides the following information:

NHS England recognises that information and support are vital to all individuals involved in the CHC process and so has funded an independent information and advice service through a social enterprise called Beacon. This service is supported by a consortium of leading voluntary sector organisations including Age UK, Parkinson's UK and the Spinal Injuries Association.

Information and advice is accessible in the form of free and comprehensive written guidance, and individuals are also able to access up to 90 minutes of free advice with a trained NHS continuing healthcare adviser 0345 548 0300. For further information and to access this service please see the Beacon website.

Further information is available on the NHS webpage on NHS continuing healthcare.

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