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BRIEFING PAPER

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NHS continuing healthcare in England

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Summary

NHS continuing healthcare is a package of health and social care arranged and funded solely by the NHS to meet physical and/or mental health needs that have arisen because of disability, accident or illness. Eligibility decisions for NHS continuing healthcare rest on whether someone's need for care is primarily due to health needs. For example, people who are eligible may have long-term complex medical conditions that require highly specialised support. Around 160,000 people in England are assessed as eligible for continuing healthcare each year.

This Commons Library briefing is intended to help Members of Parliament respond to queries from constituents about eligibility to NHS continuing healthcare in England, although equivalent provision in Scotland, Wales, and Northern Ireland are covered in the section 7 of this briefing. As services provided by the NHS are free 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 paper, Financing care home charges (SN01911), is designed to help answer constituents' queries about the local authority means-test for care home charges.

Following concerns about the local criteria used for making decisions about eligibility for NHS continuing healthcare, and challenges to the legality of individual eligibility decisions in the courts, in 2007 the Department of Health issued a National Framework for NHS continuing healthcare. This Framework was intended to improve the consistency of approach taken by local NHS bodies by providing a common framework for decision making and the resolution of disputes. The latest version of this Framework was published in March 2018 and applies from 1 October 2018.

This briefing paper provides a summary of the key areas within the National Framework and other Department of Health and Social Care guidance. Links to these documents, and briefings from other organisations, can be found at the end of this Briefing Paper. The official guidance should be consulted for a fuller account of the rules and duties that apply to NHS bodies responsible for determining eligibility for NHS continuing healthcare.

Clinical Commissioning Groups (CCGs) are responsible for commissioning NHS continuing healthcare in England, although NHS England also has commissioning responsibilities for some specified groups of people (for example, prisoners and military personnel).

Coronavirus Act 2020

The *Coronavirus Act 2020* allows NHS providers to delay assessments for NHS Continuing Healthcare (NHS CHC) until after the emergency period.

The Government has said that delaying assessments for NHS CHC will enable patients to be discharged more quickly, when clinically appropriate, to free up hospital space for those who are very ill and enable clinicians to focus on delivering care. The Impact Assessment for the Bill notes that this measure "would only be brought into operation for the shortest possible time at the peak of the coronavirus outbreak."

During the House of Commons debate on the *Coronavirus Bill*, the Secretary of State for Health & Social Care Matt Hancock said that although NHS CHC assessments will be

delayed until after the emergency period, the people who need this support will still receive NHS funding in the interim.[1]

NHS Trusts have been allocated emergency coronavirus funding to pay for people's health and care needs during this emergency period. Government guidance on hospital discharge arrangements says:

> The government has agreed the NHS will fully fund the cost of new or extended out of-hospital health and social care support packages, referred to in this guidance. This applies for people being discharged from hospital or [who] would otherwise be admitted into it, for a limited time, to enable quick and safe discharge and more generally reduce pressure on acute services.[2]

The guidance also confirms that clinicians still have a duty to assess the specific needs of highly vulnerable individuals and to commission the relevant care.[3]

1 HC Deb 23 March 2020 c42).
2 HM Government, NHS, COVID-19 Hospital Discharge Service Requirements, p3
3 HM Government, NHS, COVID-19 Hospital Discharge Service Requirements, p43

1. What is NHS continuing healthcare?

In England NHS continuing healthcare 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 continuing healthcare the NHS will be responsible for providing for all of 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 that the NHS also makes a contract with the care home and pays the full fees for the person's accommodation, board and care.

NHS-funded nursing care refers to 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 NHS continuing healthcare before a decision is reached about the need for NHS-funded nursing care.

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 by the *Health and Social Care Act 2012*) that the duty is derived. For example, section 3 of the 2006 *NHS Act* requires CCGs to provide a range of services, to such an extent as they consider necessary to meet all reasonable requirements. These services must include, amongst other categories, "such other services or facilities for the prevention of illness, the care of persons suffering from illness, and the after-care of persons who have suffered from illness as the group considers are appropriate as part of the health service."[4] The duties of CCGs and NHS England in relation to NHS continuing healthcare and NHS-funded nursing care are laid down in *The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012*.[5]

Eligibility for NHS continuing health care is not based on having a specific medical condition and eligibility places no limits on the settings in which the package of support can be offered or on the type of service delivery.[6] The actual services provided as part of a package of NHS continuing healthcare should be tailored to meet the specific needs

4 Section 3 (1)(e) of the *NHS Act 2006*.
5 As amended by *The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) (Amendment) Regulations 2013)*; paragraphs 33 to 48 of the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care (2018) provide further information on the legal framework for NHS continuing healthcare.
6 The National Framework (2018), p. 7.

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 NHS continuing healthcare. Services will depend on the needs of the individual in question and, whatever the services may be, people in receipt of NHS continuing healthcare continue to be entitled, like other people, to the usual range of NHS primary, community, and secondary care, and 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.[7] 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."[8]

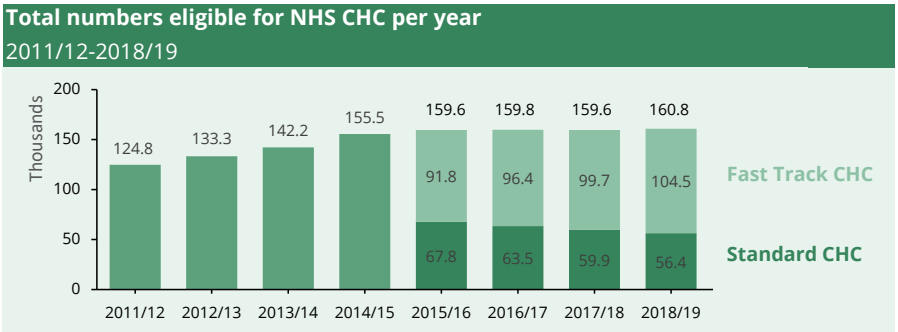
How the division of responsibility between the NHS and local social services is determined has been a major point of contention over several years and can have major repercussions for the respective expenditure of the NHS and the local social services authority. For individual patients it can mean the difference between a service that is provided 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, Financing care home charges (SN1911), is designed to help answer constituents' queries about the local authority means-test for care home charges.

7 The National Framework (2018), paragraph 19.

8 The basic role of the local authority is set out in paragraphs 25-30, and the legal framework governing the role of local authorities is set out in paragraphs 42-48 of The National Framework (2018).

2. How many people receive NHS continuing healthcare in England?

The total number of people who receive NHS continuing healthcare (NHS CHC) in England has averaged around 160,000 in the years 2015/16 to 2018/19, growing less than 1% in the same period. This period of stability in the numbers deemed eligible for NHS CHC stands in contrast to the preceding years from 2011/12. In 2011/12, around 125,000 received, or were eligible to receive, NHS CHC, rising to around 160,000 in 2015/16— representing an average year-on-year increase of 6.4%. This was faster that the rate of growth of the over-65 age group, whose numbers grew by an average of 2.7% a year between 2011/12 and 2015/16.



Source: PQ, Continuing Care: Finance: Written Question, 1 July 2019, HL 16804; National Audit Office (NAO), Investigation into NHS continuing healthcare funding (2017), pp. 21-22.

These figures include newly eligible individuals and individuals who were already eligible at the start of the year. Since 2015/16, an average of 61% of those eligible have been on the Fast Track, the pathway for those whose situation is deteriorating quickly. The numbers eligible for standard NHS continuing healthcare has fallen from 67,774 in 2015/16 to 56,395 in 2018/19— 17% lower at the end of the reported period.

In answer to a January 2019 PQ, the Government published the number of people who received continuing healthcare in each CCG in England from 2013/14 to 2017/18.[9]

In 2015/16, £4.3 billion was spent by NHS England on continuing healthcare. This had risen to £4.5 billion in 2017/18.[10]

9 PQ, Continuing Care: Written Question, 211100, 22 January 2019.
10 PQ, NHS Expenditure: Written Question, 30 January 2019, 214550

3. The National Framework

3.1 Background

The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care (the National Framework) was first published in June 2007 and became mandatory from 1 October 2007.[11] 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.[12] The Secretary of State issued directions requiring NHS bodies and local authorities to comply with key aspects of the new policy.

The National Framework was revised in November 2012 to reflect the new NHS framework and structures created by the *Health and Social Care Act 2012* effective from 1 April 2013. The 2012 Framework also incorporated the previously separate Practice Guidance, Frequently Asked Questions (FAQs) and Refunds Guidance.

Following the transfer of responsibility for NHS continuing healthcare to clinical commissioning groups (CCGs) under the 2012 Act, The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012, set out CCG and NHS England duties in this area. Regulations 21 (12) says that, in carrying out their duties, CCGs and NHS England must have regard to the National Framework. This means that they are under a legal obligation to follow the Framework unless they have a good reason not to.

In March 2018, Department of Health and Social Care published a revised National Framework. This came into force from 1 October 2018 and is designed to clarify certain aspects of the screening and assessments processes, as well as to provide more explicit guidance for CCGs and local authorities (on NHS-funded Nursing Care, inter-agency disputes, well-managed needs, and the Fast Track Pathway Tool). The eligibility criteria are unchanged.[13] The revised National Framework followed reports in July 2017 and January 2018 by the National Audit Office and the Public Accounts Committee which noted "unacceptable variation" between areas in the number of people assessed as eligible to receive NHS continuing healthcare, and in how it is being delivered.

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11 A revised version of October 2018 is currently in force. Versions are also available for 2012, 2009 and 2007. See also Written Ministerial Statement HC Deb 26 June 2007 20-21WS and Department of Health Press Notice, "Streamlining the system for NHS continuing care," 26 June 2007 (no longer available online).

12 See the final page of the Briefing Paper for a list of associated documents.

13 Department of Health and Social Care, National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care: October 2018 (Revised) (March 2018), p. 3.

3.2 The primary health need test

The central criterion for receipt of NHS continuing healthcare, as set out in the National Framework, is whether a person's primary need is a health need. In order to determine whether an individual has a primary health need, an assessment of eligibility process must be undertaken by a 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.[14]

The National Framework provides further detail but in summary, it notes that 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 expands on this, noting that

> 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. 15

The Framework also states that people should not find themselves in a situation where neither the NHS nor the relevant local authority (subject to the person's means and the person having needs that fall within the eligibility criteria for care and support) will fund their care, either separately or together.

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

> a) are no more than incidental or ancillary to the provision of accommodation which 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 judgement of 1999.[17] The National Framework summarises one of the key points from the judgement 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]

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

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14 DHSC, National framework (2018), paragraph 54.
15 Ibid. para 55
16 Ibid, paragraph 58.
17 The significance and impact of the *Coughlan* judgement is explained in Annex B of the National Framework and in a separate Library note, *Background to the National Framework for NHS Continuing Healthcare* (SN04643).
18 DHSC, National framework (2018), Appendix B, paragraph 3.

authority's 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 that the possibility of deterioration should also be taken into account. In particular, 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 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 Paper, on the Assessment Process.

As well as describing the characteristics on which eligibility should be based, the Framework includes a section on what not to base eligibility. 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;
- the need for/presence of 'specialist staff' in care delivery;

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19 Ibid, paragraph 59.
20 Ibid, paragraphs 217-223.

- 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

Clinical commissioning groups (CCGs) must carry out an assessment for NHS continuing healthcare if it seems that someone may need it. For example, the assessment should be carried out:

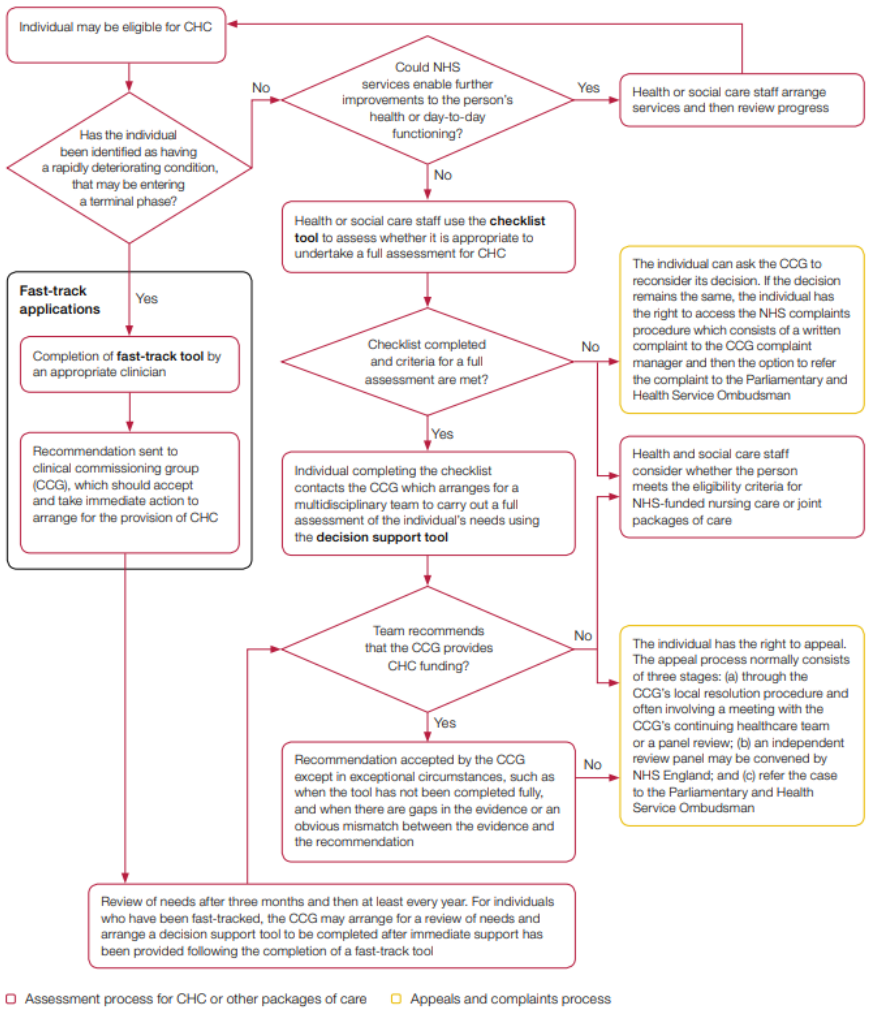
- if someone's physical or mental health worsens significantly;
- before someone is awarded NHS-funded nursing care; or
- when someone is discharged from hospital..

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 CCG NHS continuing healthcare coordinator. 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 below diagram from the 2017 NAO Investigation into NHS continuing healthcare funding, summarises the assessment and appeals process for continuing healthcare (CHC):

21 Ibid, paragraph 65.

The assessment process for CHC



Source: National Audit Office

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.

Where a patient is receiving NHS continuing healthcare a case review should be undertaken no later than three months after the initial eligibility decision, in order to reassess care needs and eligibility, and to ensure that their needs are being met. Reviews should then take place annually, as a minimum.[22] These reviews are separate from the dispute resolution reviews described in section 4 of this Briefing Paper.

Initial checklist

The first step for most people is a screening process where a nurse, doctor, a 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

22 DSHC, Public information leaflet: NHS continuing Healthcare and NHS-funded nursing care (December 2018), p. 15.

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 CCG to reconsider the decision. The CCG 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.[23]

Full Assessment and the Decision Support Tool

Full assessments should be carried out by a multidisciplinary team and, irrespective of the setting, the CCG has responsibility for coordinating the process until a decision is reached.

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 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, cognition, behaviour, drug therapies and medication, altered states of consciousness and other significant care needs.[24]

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," or "low."[25]

Indicative guidelines as to thresholds are set out in the tool (for example, if one area of need is at "priority" level, then this demonstrates a primary health need), but these are not to be viewed prescriptively. The Decision Support Tool 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 in order to improve consistency and evidenced-based decision. 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."[26]

Once the multidisciplinary team has reached agreement, it should make a recommendation to the CCG on eligibility. Only in exceptional circumstances and for clearly articulated reasons, should the CCG reject the multidisciplinary team's recommendation. A decision not to accept

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23 DSHC, National Framework (2018), paragraphs 82-107.
24 Ibid, paragraph 136.
25 DSHC, NHS Continuity healthcare decision support tool (December 2018), paragraph 20.
26 DSHC, National Framework (2018), paragraph 141.

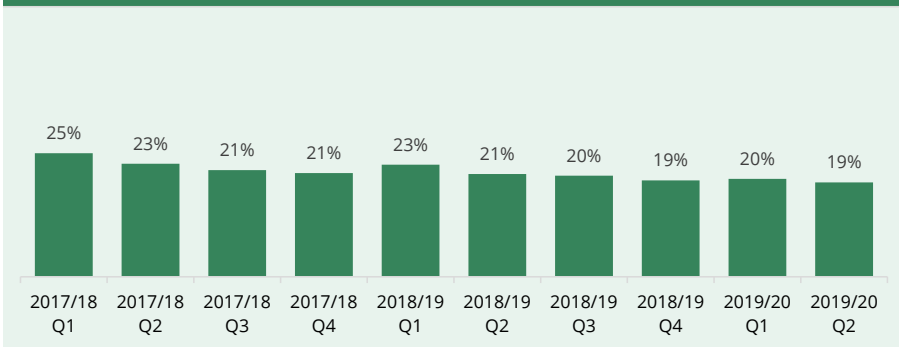
the recommendation should never be made by one person acting unilaterally.[27]

The Framework says that CCGs may choose to use a panel to ensure consistency and quality of decision making but that a panel should not fulfil a gate-keeping function. Nor should it be used as a financial monitor.[28]

The time between the Checklist (or other notification of potential eligibility) being received by the CCG 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.[29] CCGs are responsible for setting their own time period for each 'stage' of the process, including giving notices to families and responding to requests for information.[30]

As the chart below shows, the proportion of individuals who are referred for a continuing healthcare checklist who are deemed eligible for NHS continuing healthcare has remained roughly constant, averaging 21% in each quarter from the first quarter of 2017/18 to the first quarter of 2019/20.

Proportion of standard referrals for NHS CHC receiving positive decision
2017/18 to 2019/20



Source: NHS England, NHS CHC and NHS-funded Nursing Care, 'CHC and GNC- National Time Series', Table 1.2

In the full year 2018/19, there were 76,803 completed referrals for standard continuing healthcare, of which 21% were assessed eligible. This compared to 75,426 completed referrals in 2017/18, 22% of which were assessed eligible.[31] In 2011/12, an estimated 34% of people referred to a full assessment for standard continuing healthcare had been assessed as eligible, this fell to 29% in 2015/16.[32]

27 DSHC, National Framework (2018), paragraphs 153, 156.
28 Ibid, paragraph 156.
29 Ibid, paragraphs 162-164.
30 PQ, Continuing Care: Written Question, 18 February 2019, 222655
31 PQ, Continuing Care: Finance: Written Question, 1 July 2019, HL 16776
32 National Audit Office [NAO], Investigation into NHS Continuing Care (June 2017), p.10.

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.[33]

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.[34] Where a recommendation is made for an urgent package of care via the fast-track process, this should be accepted and actioned immediately by the CCG. The Framework says that 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.[35]

In both 2017/18 and 2018/19, 96% of those assessed under the Fast Track were assessed eligible. There were 91,418 assessments in 2018/19 and 87,245 in 2017/18.[36]

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

The National Framework says that "the package to be provided is that which the clinical commissioning group (CCG) assesses is appropriate for the individual's needs."[37] The public information leaflet suggests that the:

> wishes and preferred outcomes [of the individual] should be given due regard. This should include discussions about your preferred

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33 PQ, Continuing Care, 14 January 2020, 1673

34 DSHC, National Framework (2018), paragraphs 220. 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.

35 DSHC, National Framework (2018), paragraphs 238.

36 PQ, Continuing Care: Finance: Written Question, 1 July 2019, HL 16776

37 DSHC, National Framework (2018), paragraph 172.

> setting in which to receive care (e.g at home or in a care home) as well as how your needs will be met and by who.[38]

Personal health budgets: pilots and legal rights

Personal health budgets have been piloted across England for NHS continuing healthcare from 2009. From October 2014, adults eligible for NHS continuing healthcare have had the legal right to have a personal health budget.[39] CCGs have powers to offer personal health budgets for NHS continuing healthcare, either as a notional budget or a real budget held by a third party. NHS England expects that unless there are exceptional circumstances, everyone living in their own home who is in receipt of NHS continuing healthcare will have a personal health budget.[40]

In 2013, Ministers explained that the "right to have" a personal health budget would provide continuity to those previously in receipt of local authority direct payments:

> A "right to have" will guarantee that CHC and those transitioning in from social care or children's services will have continuity of care in the services they receive. Those already on NHS CHC will be able to continue to access the services they are familiar with as they will be in control of how their budget is spent and have the confidence to exercise choice. Similarly, those who are new to NHS CHC, those who transition in from social care budgets or those who transition from children's services will be able to continue to access the services they are accustomed to without the fear that this power to choose will be taken away from them when they move to a new package of care. There will continue to be people for whom PHBs are not appropriate but by giving a "right to have" we will ensure that they will only be declined on clinical or financial grounds which are deemed to make a PHB unviable.[41]

The NHS Long-Term Plan, published in January 2019, included a commitment for the NHS to accelerate the roll-out of personal health budgets and personalised care.[42]

Patient choice and personal health budgets

The National Framework states that CCGs 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 notes that cost must be balanced against other factors in the individual case, such as an individual's desire to continue

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38 DSHC, Public information leaflet: NHS continuing Healthcare and NHS-funded nursing care (December 2018), pp. 13-14.

39 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.

40 NHS England, Personal health budgets in NHS Continuing Healthcare and children and continuing care for children (accessed 14 October 2019).

41 HC Deb 8 October 2013, 16WS

42 The NHS Long Term Plan (January 2019), p. 25.

to live in a family environment.[43] The Government in 2017 stated that "the starting point for agreeing a NHS Continuing Healthcare care package and the setting where NHS Continuing Healthcare services are to be provided should be the individual's preferences."[44]

Paying for additional care

The National Framework provides guidance for NHS patients who wish to pay for additional private care, or become eligible for NHS continuing healthcare whilst living in private care home accommodation.

The guidance states that, in the first instance, the CCG should meet the patient and offer to review the care package in order to identify whether a different package would be more appropriate.[45] If an individual expresses a preference for higher-cost accommodation, the CCG should also liaise with the individual to identify reasons for their preferences.[46] The guidance provides "hairdressing, aromatherapy, beauty treatments and entertainment services" as examples of additional private services which might be purchased separately.[47]

If an individual becomes eligible for NHS continuing healthcare when already resident in a care home for which the fees are higher than the CCG would usually meet, there are some circumstances where a CCG may propose a move to different accommodation or a change in care provision. The guidelines state that the CCG should take into account the "frailty, mental health needs or other relevant needs of the individual" when determining an accommodation move.[48] A transition care plan should be developed between the old and new providers.[49]

When remaining in their own home whilst being eligible for NHS continuing healthcare, costs such as equipment provision, laundry and daily domestic tasks may be met by the CCG 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]

If an individual wishes to dispute a decision of a CCG 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 Paper).

43 DSHC, National Framework (2018), paragraphs 279-90 and p.135, at PG45.
44 PQ, NHS: Continuing Care: Written Question, 7 November 2017, 112017
45 DSHC, National Framework (2018), paragraphs 270-278.
46 Ibid, paragraph 282.
47 Ibid, paragraph 275.
48 Ibid, paragraphs 283-284.
49 Ibid, paragraphs 288.
50 Ibid, paragraphs 291-295.

4. Dispute resolution

Reviews of NHS continuing healthcare decisions

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

- A local review process at CCG level;
- A request to NHS England, which may then refer the matter to an Independent Review Panel;[51]
- 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 continuing healthcare using the Decision Support Tool, the clinical CCG should explain the person's right to request a review of the decision.

Each CCG must agree a local review process, including timescales, which should be made publicly available and a copy should be sent to anybody who requests a review of a decision.

From Quarter 1 of 2018/19 to Quarter 2 of 2019/20, an average of 18% of Local Resolutions (requests to CCGs to review an eligibility decision) resulted in the overturning of a judgment of ineligibility for NHS continuing healthcare. An average of 829 have been heard each quarter.[52]

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 CCG. 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.[53]

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 CCG 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.[54]

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51 Public Information Leaflet: NHS Continuing Healthcare and NHS-funded Nursing Care (December 2018), p. 16.

52 NHS England, NHS CHC and NHS-funded Nursing Care, 'CHC and GNC- National Time Series', Table 1.2

53 DSHC, National Framework (2018), paragraphs 194-195, 197.

54 Ibid, paragraphs 201-204. Annex D provides further details of procedures to be followed in relation to Independent Review Panels. There are also provisions

The independent review process is coordinated by the NHS continuing healthcare teams in each of the four regions of NHS England. The entirety of the previous approach was tested from 11 July 2016 to 31 October 2018. Requests for review of 'Previously Unassessed Periods of Care' cases were reviewed since 1 December 2015.[55]

In 2017/18, NHS England undertook 694 independent reviews of NHS continuing healthcare eligibility, and 642 from 1 April 2018 to 31 January 2019. It took an average of 319 days from the date of request for an Independent Review to the date of hearing in 2017/18, and an average of 417 days in 2018/19.[56]

Reviewing personal health budget decisions

If a CCG considers a personal health budget to be impracticable or inappropriate (for example, due to specialised clinical care being required), the CCG must set out in writing why the request has been refused. The patient or their representative may then request that the CCG reconsiders their decision. The CCG must reconsider the decision in a timely manner. NHS good practice states that a final decision should be made within 28 days.

Once this review is complete, CCGs should inform the individual and/or their representative of its decision in writing, setting out the reasons for its decision. If an individual and/or their representative is not satisfied they can pursue the matter via the local NHS complaints processes.[57] For more information on NHS complaints see the Library Briefing Paper on NHS complaints procedures in England and the NHS complaints page.

Disputes between providers

In 2013, NHS England published guidance on determining responsibility for payments to providers. This included guidance on transferring funding between CCGs in the event that an individual eligible for continuing healthcare moves home.[58] The guidance suggests that the 'usual residence' of the individual concerned determines the liability of the CCG. '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.[59]

If there is a dispute between CCGs, they should agree interim measures until the dispute is resolved through the local dispute resolution process. If they dispute cannot be resolved, then the matter should be forwarded to NHS England.[60] The guidance states that "no treatment should be

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regarding disputes between CCGs and local authorities about who is the responsible body to provide care (paragraphs 208-215).

55 NHS England, NHS Continuing Healthcare (May 2018).

56 PQ, Continuing Care: Reviews: Written Question, 11 March 2019, 230823

57 NHS England, Guidance on the "right to have" a Personal Health Budget (September 2014), pp. 15-16.

58 NHS England, 'Who pays? Determining responsibility for payments to providers' (August 2013), paragraphs 15-18.

59 Ibid, Annex B.

60 PQ, Continuing Care: Finance: Written Question, 22 July 2019, 280298

refused or delayed due to uncertainty or ambiguity as to which CCG is responsible for funding an individual's healthcare provision." [61]

Retrospective funding claims and refunds

The NHS continuing healthcare refreshed redress guidance published in April 2015 provides guidance for CCGs to settle claims for individuals arising from NHS continuing healthcare eligibility decisions or where an eligibility decision has been reached on a previously un-assessed period of care. The guidelines advise CCGs to calculate the interest on repayments using the Retail Price Index. [62]

In March 2012, deadlines were introduced for requests for an assessment for NHS continuing healthcare "previously unassessed periods of care" between 1 April 2004 and 31 March 2012 in England. 624 claims remained outstanding as of 30 November 2018. [63]

61 NHS England, 'Who pays? Determining responsibility for payments to providers' (August 2013), paragraph 7.
62 PQ, Continuing Care: Written Question, 7 January 2019, 206024
63 PQ, Continuing Care: Written Question, 15 January 2019, 206023

5. Refunds guidance

Annex E of The National Framework sets out the approaches to be taken by NHS England, CCGs and local authorities when a decision is awaited on eligibility for NHS continuing healthcare 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.

Two paragraphs of Annex E set out refunding guidance on where a CCG's eligibility decision is revised as a result of an individual disputing a refusal to provide NHS continuing healthcare (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 CCG should refund the local authority the costs of the care package that it has incurred during the period of unreasonable delay. The CCG 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…
>
> […]
>
> 16. Where:
>
> i) a local authority has provided care and support to an individual in circumstances where a CCG has decided that the individual is not eligible for NHS continuing healthcare, and
>
> ii) the individual disputes the decision that they are not eligible for NHS Continuing Healthcare and the CCG's decision is later revised (including where the revised decision is as a result of an IRP recommendation), the CCG should refund the local authority the costs of the care package. This should be based on the gross care package costs that the local authority has incurred from the date of the decision that the individual was not eligible for NHS Continuing Healthcare (or earlier, if that decision was unreasonably delayed – see the previous section) until the date that the revised decision comes into effect.[64]

In such cases the CCG should reimburse any costs incurred by the local authority or individual concerned.

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64 DSHC, National Framework (2018), Annex E 'Guidance on responsibilities when a decision…is awaited or disputed', paragraphs 12 and 16.

6. Recent developments

6.1 Efficiency savings

The Government's mandate to NHS England for 2018-19 included an objective that NHS England "will deliver the identified large efficiency opportunities requiring concerted action across the system…as a critical part of balancing its budget."[65]

£855 million from the budget for NHS continuing healthcare has been earmarked as an efficiency saving by the Government. January 2019 Treasury modelling expects that the efficiencies will come from the following:

- Working with the Department of Health and Social Care to provide clarity around the National Framework and improving the way CCGs deliver the National Framework. This includes interventions such as improved data and benchmarking information and reducing the number of continuing healthcare assessments in an acute hospital setting – (circa £361 million);
- Improving the commissioning of care packages – (circa £122 million);
- Improving continuing healthcare processes including the supporting of staff with Training and Development – (circa £79 million);
- CCGs locally delivered improvement initiatives – (circa £293 million).[66]

These efficiencies are planned against the background of NHS continuing healthcare spending increasing by an average of 3.9% a year from 2018 to 2020/21, or 20% over the period (though there will be variation between CCGS).[67] NHS England in March 2019 said £757 million was expected to have been achieved in efficiencies by the end of the 2018/19 financial year.[68]

The NAO report Investigation into NHS continuing healthcare funding (July 2017) stated that target spending on NHS-funded nursing care and assessment costs on continuing healthcare in England would be £4.392 billion in 2020/21, compared to £3.607 billion in 2015/16.[69]

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65 DSHC, The Government's revised mandate to NHS England for 2018-19 (May 2019), paragraph 2.8. For 2019/20, the Government published its mandate as part of the NHS Accountability Framework 2019-20 (May 2019).

66 PQ, Continuing Care: Finance: Written Question, 19 December 2018, HL12446

67 PQ, Continuing Care: Written Question, 5 June 2018, 150163

68 NHS England and NHS Improvement, Meetings in common of the Boards of NHS England and NHS Improvement (28 March 2019), paragraph 55.

69 NAO, Investigation into NHS continuing healthcare funding (July 2019), p. 29.

6.2 NHS Continuing Healthcare Strategic Improvement Programme

From April 2017 to March 2019, NHS England ran a Continuing Healthcare Strategic Improvement Programme to examine how services can be improved. The programme sought to:

- Reduce the variation in patient and carer experience of continuing healthcare assessments, eligibility and appeals.
- Ensure that assessments occur at the right time and place, with fewer assessments taking place in hospitals.
- Work with CCGs across the country to identify best practice that can be adopted by other CCGs.
- Set national standards of practice and outcome expectations.
- Make the best use of resources – offering better value for patients, the population and the tax payer.
- Strengthen the alignment between other NHS England work programmes which have a continuing healthcare component, such as Personalisation and Choice.

Minutes of the March 2019 Meeting of the Boards of NHS England and NHS Improvement state that NHS continuing healthcare expenditure was stabilising, with lower growth than forecast. £530 million were delivered in savings by CCGs in 2017/18, and £227 million was expected to be delivered in efficiencies in 2018/19 (constituting a gross impact of £757 million). The Boards stated this was achieved without changing eligibility rates.[70]

6.3 National Audit Office report

In July 2017, the National Audit Office (NAO) published its report on NHS continuing healthcare, which focused, in particular, on access. The report found that the number of people assessed as eligible for continuing healthcare grew by an average of 6.4% over the previous four years. In 2015/16, almost 160,000 people received, or were assessed as eligible for, continuing healthcare funding during the year, at a cost of £3.1 billion.[71]

The NAO report included the following key findings:

- The current assessment process for continuing healthcare "raises people's expectations about whether they will receive funding and does not make best use of assessment staff", which has been acknowledged by NHS England.
- In 2015/16, around one-third of full assessments took longer than 28 days to arrive at an eligibility decision, which is the maximum period stipulated by the National Framework.
- Eligibility decisions have a "significant financial impact on the individual, CCG, and the local authority. The CCG must pay for

[70] NHS England and NHS Improvement, Meetings in common of the Boards of NHS England and NHS Improvement (28 March 2019), paragraph 55.
[71] NAO, Investigation into NHS continuing healthcare funding (July 2019), p. 6.

someone's health and social care cost if they are assessed as eligible, "irrespective of the number of people that apply and are assessed as eligible." If they are assessed as ineligible, however, the local authority and/or the individuals may have to pay their social care costs instead.

- The number of people receiving continuing healthcare funding is rising although the proportion assessed as eligible for standard (non fast-track) continuing healthcare has reduced since 2011. In the same period, the estimated proportion of people who were referred for a full assessment which resulted in them being assessed as eligible for standard continuing healthcare fell from 34% to 29%.
- NHS continuing healthcare is a "significant cost pressure on CCG's spending." Between 2013/14 and 2015/16, spending on continuing healthcare increased by 16%. In 2015/16, continuing healthcare accounted for 4% of all CCG's total spending, and NHS England estimates that spending on continuing healthcare and related costs will increase from £3,607 million in 2015/16 to £5,247 million in 2020/21. At the same time, NHS England's efficiency plan includes a requirement for CCGs to make £855 million of savings on continuing healthcare and NHS-funded nursing care by 2020-21.
- The number of unsuccessful continuing healthcare funding applicants who appeal against initial eligibility decisions is unknown. Cases reviewed by an independent review panel, subsequent to a review by a CCG, numbered 448 in 2015/16, 27% of which resulted in NHS England recommending a different eligibility decision. In the same period, the Parliamentary and Health Service Ombudsman received 1,250 continuing healthcare funding-related complaints, 181 of which it investigated which, in turn, resulted in 36 of them being partly or fully upheld.
- There is "significant variation between CCGs in both the number and proportion of people assessed as eligible for CHC." In 2015-16, the number of people who were assessed as eligible for funding ranged from 28 to 356 people per 50,000 population. During the same period, the estimated proportion of people that were referred and subsequently assessed as eligible ranged from 41% to 86%, excluding the 5% of CCGs with the lowest and highest percentages. According to NHS England's analysis, this variation cannot fully be explained by local demographics, which according to the NAO, "suggests there may be differences in the way CCGs and local authorities are interpreting the national framework to assess whether people are eligible for CHC due to the complexity of this framework."
- There are "limited assurance processes in place to ensure that eligibility decisions are consistent, both between and within CCGs." There is quarterly reporting and self-assessment by CCGs, but limited mechanisms for ensuring individual eligibility decisions are being made consistently across CCGs, particularly as there is a shortage of data on continuing healthcare. From April

2017, however, NHS England has expanded the data it publishes on continuing healthcare.[72]

6.4 Public Accounts Committee Inquiry

Following publication of the NAO report, the House of Commons Public Accounts Committee (PAC) announced its inquiry into NHS continuing healthcare. The PAC said that it would consider developments made since July 2107 and question representatives from the Department of Health and NHS England to ask them what is being done to improve the assessment process and how NHS England's efficiency plan is affecting the spending of CCGs and the delivery of continuing healthcare.[73]

PAC report

In January 2018, PAC published its report which echoed many of the NAO's key findings with the following conclusions and recommendations:

1. Too many people are waiting too long to find out if they are eligible for CHC, and to receive the essential care that they need.[…]

   Recommendation: NHS England needs to hold CCGs to account for delays in assessments, and needs to find out the extent of further delays by CCGs in providing care packages once funding is agreed, taking remedial action where needed.

2. Some patients are not receiving the care that they are entitled to because they are not made aware of the funding available, or because the system is too difficult for them to navigate.[…]

   Recommendation: The Department and NHS England need to improve awareness of CHC amongst patients and their families, and amongst health and social care professionals, by

   - establishing where there are awareness gaps, with different patient groups and different health and social care professionals; and
   - reporting back to the committee by April 2018 on how awareness has been raised.

3. Patients' likelihood of getting CHC funding depends too much on local interpretation of assessment criteria, due to poor quality assessment tools and inadequate training.[…]

   Recommendation: The Department and NHS England should report back to the Committee by April 2018 on:

   - what action they have taken to improve the quality of assessment tools and training for staff carrying out assessments; and
   - how it plans to monitor the impact of these changes on reducing variation between CCGs.

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72 NAO, Investigation into NHS continuing healthcare funding (July 2019), pp. 8-11.
73 Public Accounts Committee, Investigation into NHS continuing healthcare funding webpage

4. NHS England is not adequately carrying out its responsibility to ensure CCGs are complying with the legal requirement to provide CHC to those that are eligible.[…]

   Recommendation: NHS England needs to establish a consistent oversight process, using the new data available, to ensure eligibility decisions are being made consistently both within and across CCGs, including by setting out what criteria they will use to identify and investigate outliers, and undertaking an annual sample audit.

5. It is not clear how CCGs can make £855 million in efficiency savings by 2020–21 without restricting access to care, either by increasing eligibility thresholds or by limiting the care packages available.[…]

   Recommendation: NHS England should provide us, by April 2018, with a costed breakdown of how these efficiency savings will be achieved, and assurance that they will not be achieved by restricting access to care for vulnerable patients.[74]

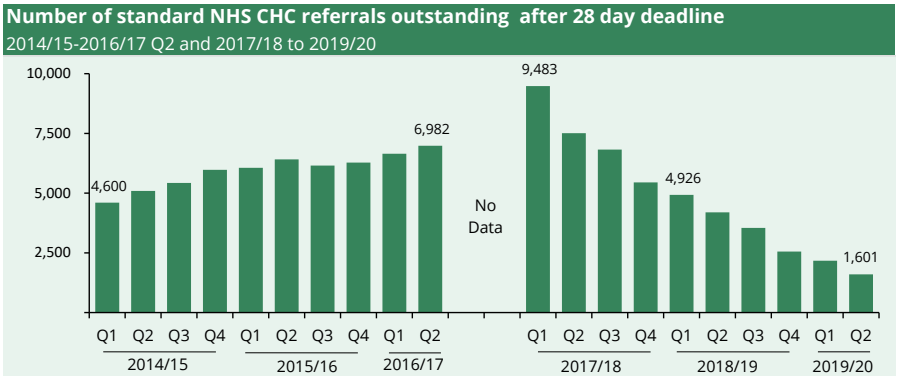
The Government's response

The Government responded formally to these conclusions and recommendations in March 2018. It agreed with all the PAC report's recommendations, although it disagreed with the conclusion that NHS is not carrying out adequately its responsibility to ensure CCGs are complying with their legal requirements around continuing healthcare.[75]

The Government committed NHS England to "regularly monitor" the efficiency of its assurance processes to ensure eligibility decisions are made consistently, with a standard that more than 80% of cases should be assessed within 28 days.[76] While data on the time elapsing between eligibility decisions being made and care packages being provided is not collected, the Government stated that NHS England would work to understand the "scale of the issue" with the possibility of developing other assurance mechanisms. This work was given the deadline of summer 2018.[77]

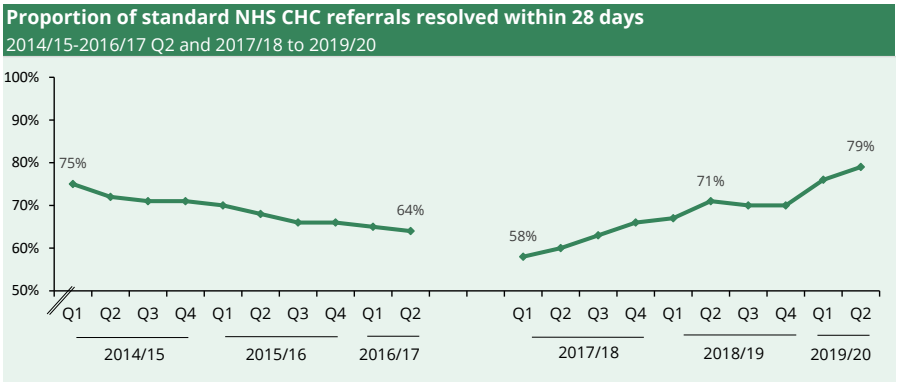
As the below chart shows, the number of NHS continuing healthcare referrals outstanding after 28 days was 51% greater in Quarter 2 of 2016/17 than in Quarter 1 of 2014/15 (rising from 4,600 individuals to 6,982). Data before 2016/17 was made available in a NAO report, whilst the NHS has published data from the first quarter of 2017/18. The number of outstanding NHS continuing healthcare referrals fell from 9,483 in Quarter 1 of 2017/18 to 1,601 in Quarter 1 of 2019/20.

74 Committee of Public Accounts, NHS continuing healthcare funding, HC 455 (17 January 2018), pp. 5-7.
75 HM Treasury, Government response to the Committee of Public Accounts, CM 9596 (March 2018), p. 16.
76 PQ, Continuing Care: Written Question, 13 April 2018, 135662
77 HM Treasury, Government response to the Committee of Public Accounts, CM 9596 (March 2018), p. 14.



Source: NHS England, NHS CHC and NHS-funded Nursing Care, 'CHC and GNC- National Time Series', Table 1.2; NAO, Investigation into NHS continuing healthcare funding (2017), p. 19.

In terms of the proportion of standard NHS continuing healthcare referrals resolved within 28 days, 75% were resolved within 28 days during Quarter 2 of 2014/15, falling to 64% during Quarter 2 of 2016/17. There has been a rise in the proportion resolved within 28 days since Quarter 1 of 2017/18, rising from a low of 58% to 79% in Quarter 2 of 2019/20.



Source: NHS England, NHS CHC and NHS-funded Nursing Care, 'CHC and GNC- National Time Series', Table 1.2; NAO, Investigation into NHS continuing healthcare funding (2017), p. 19.

The Government committed to working with NHS England to "understand the awareness gap" with regard to the NHS continuing healthcare process in assessing eligibility.[78]

The Government notified PAC that it had published a revised National Framework for NHS continuing healthcare and NHS-funded Nursing Care, which it said would become operational on 1 October 2018. It committed NHS England to review checklist tools, and announced that the Department of Health and Social Care and NHS England had launched a programme to explore the initial pathway. It also remarked that NHS England's national workforce programme would support the continuing healthcare assessment process which would develop a competency framework for CCGs.

Whilst it argued that there will always be variation in the number of continuing healthcare assessments for multiple reasons, including variations in geographical age dispersion and health needs, the

78 HM Treasury, Government response to the Committee of Public Accounts, CM 9596 (March 2018), p. 15.

Government noted that NHS England intends to carry out work to understand the nature of variation. It also noted that NHS England is developing a pilot as test for a "sustainable national NHS CHC case-level audit for England" to ensure the quality, consistency and fairness of services being provided within and between CCGs.[79]

The Government stated what steps it was taking to ensure greater consistency between CCGs in the granting of NHS continuing healthcare in answer to a September 2019 PQ:

> There will always be some variation across clinical commissioning groups (CCGs) in NHS Continuing Healthcare eligibility (NHS CHC), due to a wide variety of reasons, including, but not limited to, the age dispersion within the local population and variations between geographical areas in terms of their level of health need.
>
> In 2017 NHS England launched an NHS CHC Strategic Improvement Programme and is helping CCGs to improve their application of the NHS CHC National Framework. The Programme aims are to provide fair access to CHC in a way which ensures better outcomes, better experience, and better use of resources.
>
> As part of this programme NHS England is working with NHS CCGs to address variation in performance and NHS CHC eligibility rates. To better understand the nature of variation in eligibility, NHS England has developed a clustering methodology, which groups together NHS CCGs with similar demographics. Additionally, the national CHC e-learning offer has been extended and enhanced, and a national competency framework developed to support CHC staff to deliver the National Framework consistently.[80]

6.5 Revised National Framework – October 2018

The Department of Health and Social Care published a revised National Framework for Continuing Healthcare and NHS-funded Nursing Care in March 2018, and which came into force in October 2018. It does not change any of the eligibility criteria, but it is designed to provide greater clarity around the assessment process and the role of CCGs and local authorities, as well as to reflect the implementation of the *Care Act 2014*. Aspects of the guidance that have been amended include:

a) Setting out that the majority of NHS Continuing Healthcare assessments should take place outside of acute hospital settings. This will support accurate assessments of need and reduce unnecessary stays in hospital.

b) Providing additional advice for staff on when individuals do and do not need to be screened for NHS Continuing Healthcare in order to reduce unnecessary assessment processes and respond to a call for greater clarity on this.

c) Clarifying that the main purpose of three and 12 month reviews is to review the appropriateness of

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79 Ibid, p. 16.
80 PQ, Continuing Care: Written Question, 286348, 3 September 2019

the care package, rather than reassess eligibility. This should reduce unnecessary re-assessments.

d) Introducing new principles for CCGs regarding the local resolution process for situations where individuals request a review of an eligibility decision. The aim is to resolve such situations earlier and more consistently.

e) Providing clearer guidance, including dedicated sections, on: the roles of CCGs and local authorities, NHS-funded Nursing Care, inter-agency disputes, well-managed needs, and the Fast Track Pathway Tool.[81]

6.6 Campaign for improvements

The Continuing Healthcare Alliance is a group of 17 charities and organisations who "believe that NHS continuing healthcare needs to improve" and who "aim to make continuing healthcare fairer and easier to access for those who need it most."

This group arose from a 2013 inquiry on NHS continuing healthcare in England conducted by the All Party Parliamentary Group (APPG) on Parkinson's. Many of those which gave evidence to this inquiry subsequently joined to form this alliance. In November 2016, it published a report – Continuing to care? Is NHS continuing healthcare supporting the people who need it in England? – which had been written in association with Parkinson's UK and which argued that the system "is failing people across England." It produced the following findings:

- 40% of professionals who completed our survey told us that their experience of decision making in a multidisciplinary team (MDT) can be very mixed. In some assessments opinions are weighted equally, while in others they are not.
- 66% of survey respondents felt the professionals in the assessment did not possess any in-depth knowledge – or knew very little – about the condition the person being assessed was living with.
- 80% of professionals surveyed said the Decision Support Tool (DST) was not fit for purpose, or there was room for improvement in some areas.
- Those with well-managed needs are often assessed as being ineligible despite having needs that qualify. Denial or withdrawal of care could result in making their needs worse.
- 42% of survey respondents who had applied for NHS CHC told us they waited more than 28 days (the deadline set by the National Framework) to receive their final decision regarding eligibility.
- 35% of survey respondents told us they had been told by the multidisciplinary team that eligibility would be

[81] DHSC, National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care: October 2018 (Revised) (October 2018), p. 3.

recommended, only to have that decision rejected by the review panel.

- Some CCGs are introducing policies that force people into care homes if the cost of their care is more than a residential care package, irrespective of whether this approach meets their assessed needs.
- When less funding is received patients can be transferred to another care company, resulting in the loss of professional carers that the person and their family know and trust.
- 44% of people surveyed had gone through at least one reassessment after being awarded NHS CHC.[82]

It recommended that, in order to make improvements to the system, the Department of Health, NHS England, CCGs, and local authorities should do the following:

- Ensure multidisciplinary teams are composed of professionals who are experienced when making decisions around NHS CHC, with knowledge of the person, their condition(s), needs and aspirations.
- Design and deliver a mandatory programme of training for professionals who organise and assess people for NHS CHC to ensure they understand the eligibility criteria and how to use the current decision tools.
- Rewrite the checklist and Decision Support Tool so they more effectively measure individuals' healthcare needs against the lawful limit of care that the local authority can provide.
- Introduce an option for professionals to select if they agree that someone should not be reassessed for eligibility of NHS CHC. For people marked down as permanently eligible, reviews should only look at changing needs, for example, where someone may need increased support.
- Prevent people with long-term, serious health conditions being forced into residential care, or living at home with unsafe levels of care, by ensuring packages of care are needs-driven and not purely financially motivated.
- Publish data on how many people apply for NHS CHC – whether they are successful or not – as well as the number of people who proceed past the checklist stage to the full assessment.[83]

The Government engaged with the Continuing Healthcare Alliance during the process of updating the National Framework.[84]

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82 Parkinson's UK and Continuing Healthcare Alliance, Continuing to care? Is NHS continuing healthcare supporting the people who need it in England? (November 2016), p. 4.

83 Ibid, p. 28.

84 PQ, Continuing Care: Finance: Written Question, 1 February 2018, 126179

7. NHS continuing healthcare in other parts of the UK

7.1 Wales

Current System

Continuing NHS Healthcare exists in Wales in a similar form to that in England. Instead of CCGs, however, 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 revision of the Welsh National Framework was completed on 29 June 2014.[85]

The Welsh Government has stated that around 5,000 people in Wales receive Continuing NHS Healthcare at any one point, costing £360 million annually.[86] In 2017/18, Continuing NHS Healthcare represented 2.2% of the Welsh NHS budget.[87]

Age Cymru have published a factsheet on NHS Continuing Healthcare and NHS-funded nursing care in Wales (November 2018).The Welsh Assembly produced a briefing Continuing NHS Healthcare in Wales- what do I need to know? (June 2016).

Reforms and Consultation

A report by the National Assembly Public Accounts Committee in March 2015, Implementation of the National Framework for Continuing NHS Health Care: Follow Up Report made seven recommendations to improve the delivery of continuing NHS healthcare in Wales. A response was provided by the Director General and Chief Executive of NHS Wales and an update on progress was given in 2016.

The Welsh Assembly Health, Social Care and Sport Committee was told by the Older People's Commissioner for Wales, Heléna Herklots, in 2018 that the "continuing healthcare system is incredibly complex to get into—the assessment process, the appeal process, what it puts families and individuals through."[88]

The Motor Neurone Disease Association published No Time to Waste in January 2019. It recommended that the Welsh Government:

- Make CHC a Healthier Wales priority area.
- Take urgent action to ensure CHC assessment is not a 'harrowing' experience for individuals and families.

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85 Welsh Government, Continuing NHS Healthcare The National Framework for Implementation in Wales (June 2014).
86 Welsh Government, Consultation: Continuing NHS Healthcare (2019), p. 5.
87 Statistics for Wales, NHS Expenditure Budgets, 2017-18 (April 2019).
88 Health, Social Care and Sport Committee, Meeting of 15 November 2018, paragraph 355

- Revise the National Framework for Implementation of CHC in Wales.
- Address the limitations of the Decision Support Tool.
- Increase the availability of trained care workers and nursing staff.

The Welsh Government launched a consultation for a new framework for continuing NHS healthcare and a summary of responses were published in November 2019. On next steps, the Welsh Government stated:

> In general, we received positive **responses to the consultation** and many agreed the document provided additional clarification in key areas. A few stakeholders were concerned that some areas needed additional clarity to enable the effective and equitable implementation of CHC. Further work will take place on the revised Framework in the coming weeks to address these concerns. A number of respondents suggested reviewing the policy framework for Funded Nursing Care policy in 2020/21. We intend to do this in 2020, after the new CHC framework is in place.
>
> There continues to be concerns regarding an individual's ability to exercise voice and control to decide how, when and who supports them to meet their eligible care and support needs when transitioning from direct payments to CHC. We shall set up a working group in the next few weeks to explore the options available to us and consider how we can best effect change in this area. We will review and address any remaining legislative barriers preventing local health boards and local authorities to use pooled funds to deliver integrated person-centred health and social care. We will look at the feasibility of introducing independent user trusts in Wales as one mechanism to support individuals to manage their health and social care needs. The clear, unambiguous expectation in Wales must be personalised, seamless integrated health and social care that enables an individual to maintain continuity of their voice and control, including the personnel delivering their care, where the individual wishes this to be the case.

The Welsh Government also intends to publish a public information booklet, providing the public with a step-by-step explanation of the CHC process. The revised framework and associated documents are intended to be published in April 2020.[89]

7.2 Scotland

2015 Reforms

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.[90]

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89 Welsh Minister for Health and Social Services, Written Statement: Continuing NHS Healthcare- The National Framework for Wales- Consultation Report, 29 November 2019

90 Scottish Government, Independent Review of NHS Continuing Healthcare (May 2014).

According to the Scottish Government's guidance, 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 the community while ensuring that all health or social care needs are supported."

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.[91]

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."[92] This change was part of the integration of health and social care in Scotland starting from April 2015.

Sources of Advice

Age Scotland have produced a guide to Hospital based complex clinical care (November 2017) and Care Information Scotland has a webpage.

7.3 Northern Ireland

Current System

Continuing healthcare is available in Northern Ireland, although in a context where 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.[93]

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

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91 Scottish Government, Hospital Based Complex Clinical Care Guidance (May 2015), pp. 2-6.
92 Ibid, p. 2.
93 Department of Health, Social Services and Public Safety, Care Management, Provision of Services and Charging Guidance (11 March 2010), p. 5.

independent living. If 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.[94]

Reports

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 that 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."[95]

In response to this, the Department carried out a comprehensive review before publishing a consultation document in 2017.[96]

This considered a number of 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.[97]

The Department consulted on the review between 19 June and 15 September 2017, but owing to there being no Northern Ireland Executive between January 2017 and January 2020, there has been no further action as yet.

7.4 Patients who move across borders in the UK

NHS England guidance, Who Pays? Determining responsibility for payments to providers, provides some guidance on the transfer of English NHS continuing healthcare patients across borders within the UK:

94 Department of Health, Continuing Healthcare Consultation- Consultation Document (2017), p. 2.
95 Age NI, The Denial of NHS Continuing Health in Northern Ireland (May 2014), p. 28.
96 Northern Ireland Department of Health, Continuing Healthcare in Northern Ireland: Introducing a Transparent and Fair System: Consultation Document (June 2017).
97 Ibid, pp. 6-11.

Scotland

65. Where an English CCG ('the placing CCG'), arranges a package of NHS Continuing Healthcare (other than a package that is only NHS-funded nursing care) the placing CCG will remain responsible for that person's CHC until that episode of care has ended. For example, the individual's health may subsequently improve rendering them no longer eligible for NHS Continuing Healthcare. In these circumstances if the individual wishes to remain in that care setting responsibility would then fall to the Health Board (and local authority) where they are usually resident.

66. The placing CCG should ensure that responsibilities are agreed before the patient is moved to ensure that continuity of care is maintained. CCGs responsible for placing a person in a Scottish Health Board area should therefore inform the receiving Health Board of the placement as soon as practicable. Arrangements for NHS nursing care differ between England and Scotland.

67. In England the CCG makes a flat rate contribution towards the cost of an individual's registered nursing care. In Scotland personal and nursing care are provided free of charge. When a Scottish Health Board makes a placement in England, the individual will be eligible for personal and nursing care payments from the Scottish placing authority

Wales

68. As set out in the protocol between England and Wales[98] where a CCG or LHB arranges a package of NHS Continuing Healthcare (other than a package that is only NHS-funded nursing care), the placing body will remain responsible for that person's continuing healthcare until that episode of care has ended. Transfer of NHS-funded nursing care patients across borders within UK

Transfer of NHS-funded nursing care patients across borders within UK

69. Arrangements are currently being explored with Scotland and Northern Ireland and this guidance will be updated in due course.[99]

98 Available at NHS England, Information on cross-border Healthcare for the NHS in England and Wales (accessed 14 October 2019).

99 NHS England, Who pays? Determining responsibility for payments to providers (August 2013), paragraphs 65-69.

8. Key guidance documents

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

- National framework for NHS continuing healthcare and NHS funded nursing care (revised October 2018): This sets out principles and processes for establishing eligibility.
- NHS continuing healthcare: checklist (March 2018): This is a screening tool to help establish who might need a full assessment of eligibility.
- Decision support tool for NHS continuing healthcare (revised March 2016): This is a detailed questionnaire to help assess eligibility.
- NHS Continuing Healthcare Decision Support Tool (March 2018)
- Fast track pathway tool for NHS continuing healthcare (March 2018): This is for urgent assessments of those with rapidly deteriorating, possibly terminal, conditions.
- NHS-funded nursing care best practice guidance (November 2018)
- Delayed discharges directions (continuing care) directions (November 2013, amended December 2018)

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

- Department of Health Public Information Leaflet: NHS Continuing Healthcare and NHS Funded Nursing Care (January 2020)
- NHS website: NHS Continuing Healthcare
- Age UK, Factsheet 20, NHS continuing healthcare and NHS-funded nursing care (October 2018)
- Alzheimer's Society, When does the NHS pay for care? Guidance on eligibility for NHS continuing healthcare funding in England, (revised October 2019)
- Beacon CHC, an independent support service funded by the NHS, Should you appeal a continuing healthcare decision? (15 January 2018). They provide 90 minutes of free advice from staff on their contact details.

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