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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 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 complex medical conditions that require highly specialised nursing support.

This Commons Library briefing is intended to help Members respond to queries from constituents about eligibility to NHS continuing healthcare in England, although equivalent provision in Scotland, Wales, and Northern Ireland is covered in the sixth section. 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 will be in operation from 1 October 2018.

This briefing paper provides a summary of the key areas within the National Framework and other important Department of Health and Social Care documents. Links to these documents, and briefings from other organisations, can be found at the end of this note. 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 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).

NHS continuing healthcare in England was recently the subject of a report authored by the National Audit Office, published in July 2017, as well as an inquiry undertaken by the Public Accounts Committee, which reported in January 2018. Both these reports were critical in particular of the difficulties experienced by individuals in accessing NHS continuing healthcare. In its response, published in March 2018, the Government accepted many of these criticisms and set out further work to improve the accessibility and efficacy of the current system and its processes. This briefing paper details the findings and recommendations of these reports, as well as the Government's response to them.

A separate Library briefing paper, *Background to the National Framework for NHS Continuing Healthcare* (SN04643) provides an account of the preceding guidance and case law.

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'. 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 NHS funding provided to support the provision of nursing care to individuals living in care homes. 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 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".[1] 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*.[2]

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.[3] The actual services provided as part of a package of NHS continuing healthcare 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 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

1 Section 3 (1)(e) of the *NHS Act 2006*
2 SI 2012/2996; paragraphs 18 to 29 of the *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care* provide further information on the legal framework for NHS continuing healthcare.
3 The National Framework (2012), para 13

people, to the usual range of NHS primary, community, and secondary care, and other NHS services.

Someone may have a package of support provided or funded by both the NHS and the local authority, this is known as a 'joint package' of continuing care. Local authority social services have duties to provide welfare services, for example, 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."[4]

How the division of responsibility between the NHS and local social services is determined has been a major point of contention over the 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.

[4] The basic legal framework governing social services is summarised in paragraphs 18 to 29 of the National Framework.

2. The National Framework

2.1 Background

The *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care* (the National Framework) was first published in June 2007[5] and became mandatory from 1 October 2007. Instead of different areas 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.[6] The Secretary of State issued Directions requiring NHS bodies and local authorities to comply with key aspects of the new policy. Following the transfer of responsibility for NHS continuing healthcare to clinical commissioning groups (CCGs) in April 2013, *The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012*,[7] set out CCG and NHS England duties in this area. Regulation 12 says that in carrying out duties CCGs and NHS England must have regard to the National Framework, which means they are under a legal obligation to follow the Framework unless they have a good reason not to.

As well as dealing with the arrangements for NHS continuing healthcare, the National Framework simplified the arrangements for NHS-funded nursing care (that is, care 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). The National Framework made clear that 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.

Following a Government commitment to review the National Framework after one year, a revised Framework was published in July 2009. The main changes concerned fast track treatment for people with a rapidly deteriorating condition entering a terminal phase. The revised document also includes some changes to processes, for example, in relation to obtaining a review of an initial screening decision, but the main basis of eligibility was not changed. The National Framework was revised again 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.

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5 The version of the *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care* which is currently in operation was published in November 2012. It will be replaced by a revised version in October 2018. It was previously revised in 2009 and this 2009 edition is the earliest version available online. 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).

6 See the final page of the note for a list of the current associated documents.

7 SI 2012/2996

In March 2018, following reports in July 2017 and January 2018 by the National Audit Office and the Public Accounts Committee which suggested that not everyone who is entitled to CHC funding is receiving it, and that there is inconsistency across CCGs in how it is being delivered, the Department of Health & Social Care published a revised National Framework. This will be implemented 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, local authorities, NHS-funded Nursing Care, inter-agency disputes, well-managed needs, and the Fast Track Pathway Tool. The eligibility criteria are unchanged.[8]

2.2 Who is eligible? The *primary health need* test

The central criterion for receipt of NHS continuing healthcare, set out in the National Framework, is whether a person's primary need is a health need:

> Where a person has been assessed to have a 'primary health need', they are eligible for NHS continuing healthcare. Deciding whether this is the case involves looking at the totality of the relevant needs. Where an individual has a primary health need and is therefore eligible for NHS continuing healthcare, the NHS is responsible for providing all of that individual's assessed health and social care needs – including accommodation, if that is part of the overall need.[9]

The Framework document expands on this, saying that as there should be no gap in the provision of care, the *primary health need* test is partly dependent on the limits of a local authority's responsibilities. This, it says, means that the test should be applied in such a way that a decision of ineligibility is only possible where, taken as a whole, the nursing or other health services required by the individual satisfy the definition of what a local social services authority might provide, as established by the *Coughlan* judgement[10]. In other words, a decision of ineligibility is only possible where the health services:

a. are no more than incidental or ancillary to the provision of accommodation which LA social services are, or would be but for a person's means, under a duty to provide; and

b. are not of a nature beyond which an LA whose primary responsibility it is to provide social services could be expected to provide.[11]

The National Framework adds that there are limitations to this test as neither the CCG or local authority can dictate what the other agency should provide. In addition, the *Coughlan* judgment focused only on

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8 Department of Health and Social Care, *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care: October 2018 (Revised)*, March 2018, p3

9 National Framework 2012, para 33

10 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).

11 National Framework 2012, para 30

general and registered nursing needs. A practical approach to eligibility was therefore required, including situations in which the 'incidental or ancillary' test was not applicable because, for example, the person would be cared for in their own home.[12]

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 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.[13]

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 has published a Fast Track Tool to help decide eligibility where this may be the case.[14] In order to minimise variation in the interpretation of these factors, the Department of Health has published a Decision Support Tool. Further information about the Decision Support Tool and the Fast Track Tool is outlined in section 2.3 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;

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12 *Ibid.* para 35
13 *Ibid.*
14 *Ibid.* paras 97 – 107

- 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;
- 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.[15]

2.3 Assessment Process: 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
- when someone is discharged from hospital. This should happen before the person is assessed for help from their local authority.

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 clinical commissioning group 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, because for example if 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.

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. These reviews are separate from the dispute resolution reviews described in part 3 of this note.

Initial checklist

The first step for most people is a screening process where a nurse, doctor other qualified healthcare professional or social worker applies a *Checklist* to see if the individual needs a full assessment of eligibility.[16]

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15 *Ibid.* para 58
16 DH, *NHS continuing healthcare* checklist, November 2012

Whatever the outcome of the *Checklis*t 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 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.

Full Assessment and the Decision Support Tool

Full assessments should be carried out by a multidisciplinary team and, irrespective of the setting, the clinical commissioning group (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 2.2 on the *primary health need* test above). In order to do this, the *Decision Support Tool*[17] provides a framework for recording the person's needs in 12 generic areas. The 12 areas are: behaviour, cognition, psychological and emotional needs, communication, mobility, nutrition (food and drink), continence, skin (including tissue viability), breathing, drug therapies and medication (symptom control), altered states of consciousness, other significant care needs. 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".

Indicative guidelines as to threshold are set out in the tool (for example, if one area of need is at Priority level, then this demonstrates a primary health need), but these are not to be viewed prescriptively. 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 "Professional judgment should be exercised in all cases to ensure that the individual's overall level of need is correctly determined."[18]

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 and a decision not to accept the recommendation should never be made by one person acting unilaterally.

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

[17] DH, *Decision Support Tool*, revised November 2012
[18] National Framework, para 88

fulfil a gate-keeping function. Nor should it be used as a financial monitor. [19]

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.

Deteriorating conditions and the Fast Track Pathway Tool

The *Fast Track Pathway Tool*[20] is designed for assessing individual who need urgent attention because they have a rapidly deteriorating condition that may be entering a terminal phase with an increasing level of dependency. 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.[21] 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.

2.4 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".[22] Practice guidance states, however, that it is necessary to take full account of the individual's own views of their needs and their preference as to how they should be met and that they "should be given as much choice as possible, particularly in the care planning process."[23]

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. Direct payments for NHS continuing healthcare have been piloted in sites approved by the Secretary of State. In October 2011, the

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19 *Ibid.* para 91
20 DH, *Fast Track Pathway Tool for NHS continuing healthcare*, November 2012
21 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*.
22 The National Framework, para 167
23 *Ibid*. Part 2 Practice Guidance PG4

previous Health Secretary Andrew Lansley announced that, subject to the evaluation of these pilots, by April 2014 everyone who is eligible for NHS continuing healthcare will have the right to ask for a personal health budget including a direct payment (although granting one would be at the discretion of the CCG).[24] This commitment was confirmed in November 2012, following the publication of the independent evaluation of the pilot programme.

On the 8 October 2013 Ministers announced that from October 2014 people in receipt of NHS continuing healthcare will further be given the "right to have" a personal health budget. Ministers explained that this 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.[25]

The National Framework practice guidance provides some additional information about the limits that can be put on individual choice where, if followed, this would result in the NHS paying for a more expensive care arrangement, and the circumstances under which a CCG can decline to provide care in the preferred setting of the individual. The practice guidance notes that cost has to be balanced against other factors in the individual case, such as an individual's desire to continue to live in a family environment.[26] The practice guidance provides information on the respective responsibilities of the NHS and local authorities when a person is supported in their own home.[27] The most recent Alzheimer's Society guidance notes that:

> It has often been assumed that people in residential care homes (as opposed to nursing homes) are not eligible to receive NHS continuing healthcare. This assumption was based on the view that people with the most serious medical conditions and complex care arrangements would be cared for in a nursing home, rather than a residential home.
>
> In fact, there are many people in residential homes with complex medical conditions who may be eligible for NHS continuing

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24 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.

25 HC Deb 8 October 2013, 16WS

26 National Framework, Part 2 Practice Guidance PG83

27 *Ibid.*

healthcare. However, because of the way their needs are assessed, it may not be easy for them to receive it.[28]

[28] Alzheimer's Society, *When does the NHS pay for care? Guidance on eligibility for NHS continuing healthcare funding in England,* October 2017 p18

3. Dispute resolution

In England, the formal responsibility for informing individuals of the decision about eligibility for NHS continuing healthcare, and their right to request a review, lies with clinical commissioning groups (CCGs). There are two 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; and
- A request to NHS England, which may then refer the matter to an Independent Review Panel.

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. It is up to each CCG to 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. 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.

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 (gathering of available evidence etc.).[29] An individual's right under existing NHS complaints procedures and his or her existing right to refer a case to the Health Service Ombudsman is not affected by the IRP procedures.

The independent review process is coordinated by the NHS Continuing Healthcare teams in each of the four regions of NHS England. The current independent review process is undergoing testing which began on 1 December 2015 and will continue until 31 March 2018, and since 11 July 2016 this has included all requests for independent review, having initially only covered requests for review of 'Previously Unassessed Periods of Care' cases.[30]

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29 *Ibid.* para 145 - 158; Annex E of the Framework provides further details of procedures to be followed in relation to Independent Review Panels. There are also provisions regarding disputes between CCGs and local authorities about who is the responsible body to provide care.

30 NHS England, NHS Continuing Healthcare webpage.

4. Refunds guidance

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.

This section of the Framework includes 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). In such cases the CCG should reimburse any costs incurred by the local authority or individual concerned.

5. Recent developments

5.1 Efficiency savings

The Government's mandate to NHS England for 2016-17 included the provision that the latter is expected to "deliver necessary efficiencies" to ensure "the NHS balances its budget".[31] In *Next steps on the NHS Five Year Forward View*, published in March 2017, NHS England identified "large efficiency opportunities that now require concerted actions rights across the NHS".[32] As part of this, NHS England expects CCGs to make £855 million of savings on NHS continuing healthcare and NHS-funded nursing care from 2015-16 to 2020-21 against its predicted growth in spending of £1.64 billion (45%). This figure was confirmed by the National Audit Office in its report published in July 2017 (about which more below). This would mean that national English spending in 2020-21 would be £4.392 billion, compared to £3.607 billion in 2015-16.[33]

5.2 NHS CHC Strategic Improvement Programme

NHS England launched an NHS CHC Strategic Improvement Programme in April 2017 to examine how CHC services can be improved. This will run for two years until March 2019 and seeks to:

- Reduce the variation in patient and carer experience of CHC assessments, eligibility and appeals.
- Ensure that assessments occur at the right time and place, with fewer assessments taking place in hospitals.
- Work with Clinical Commissioning Groups (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 CHC component, such as Personalisation and Choice.

5.3 National Audit Office report

In July 2017, the National Audit Office (NAO) published its report on NHS continuing healthcare and, "in particular, access to CHC funding". This reported that the number of people assessed as eligible for CHC funding "has been growing by an average of 6.4% a year over the last four years". It also reported that in 2015-16, "almost 160,000 people received, or were assessed as eligible for, CHC funding during the year,

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31 Department of Health, *The Government's mandate to NHS England for 2016-17, March 2017*, p9

32 NHS England,

33 National Audit Office [NAO], *Investigation into NHS continuing healthcare funding*, HC 239, July 2017, p29

at a cost of £3.1 billion".[34] Overall, it reported nine key findings, which included the following:

- The current assessment process for CHC funding "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. Overall, NHS England estimated that "only about 18%" of screenings conducted in 2015-16 led to the person being assessed as eligible for CHC.
- 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, clinical commissioning group, and the local authority. The CCG must pay for 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 CHC funding is rising although the proportion assessed as eligible for standard (non fast-track) CHC has reduced since 2011". Between 2011-12 and 2015-16, the number of people who received or were eligible to receive funding increased from 125,000 to 160,000. 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 CHC fell from 34% to 29%.
- CHC is a "significant cost pressure on CCG's spending". Between 2013-14 and 2015-16, spending on CHC increased by 16%. In the latter period, CHC accounted for 4% of all CCG's total spending, and NHS England estimates that spending on CHC and related costs will increase from £3,607 million in 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 CHC and NHS-funded nursing care by 2020-21. "NHS England assumes that increasing both consistency and the number of people assessed after being discharged from hospital will result in CCGs providing CHC funding to fewer patients".
- The number of unsuccessful CHC 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 CHC 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

[34] *Ibid*., p6

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 CHC. From April 2017, however, NHS England has expanded the data it publishes on CHC.[35]

5.4 Public Accounts Committee Inquiry

Following publication of the NAO report, the House of Commons Public Accounts Committee (PAC) announced its inquiry into NHS CHC, and said that it would "consider developments made on CHC since July 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 CHC.[36]

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*

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35 *Ibid*., pp8-11

36 Public Accounts Committee, *Investigation into NHS continuing healthcare funding webpage*

- 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*.

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*.[37]

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 expressly disagreed with the conclusion that NHS is not carrying out adequately its responsibility to ensure CCGs are complying with their legal requirements around CHC.

The Government committed NHS England to "regularly monitor" the efficacy 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. 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.

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[37] Committee of Public Accounts, *NHS continuing healthcare funding*, HC 455, 17 January 2018, pp5-7

The Government committed to working with NHS England to "understand the awareness gap" with regard to the NHS CHC process in assessing eligibility, and to devise a plan of action on this by summer 2018 before reporting back to PAC.

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

Whilst it argued that there will always be variation in the number of CHC assessments for multiple reasons, including variations in geographical age dispersion and health needs, the 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 CHC services being provided within and between CCGs, which is in underway and expected to conclude in December 2018.

On its proposed efficiency savings, the Government estimated notional efficiency opportunities of £855 million by 2020/21 by

- giving clarity to the National Framework and improving how CCGs deliver it (circa £361 million);
- improving commissioning care packages (circa £122 million);
- improving the CHC process (circa £79 million); as well as
- through improvement initiatives carried out locally by CCGs (circa £293 million).[38]

5.5 Revised National Framework – October 2018

The Department of Health & Social Care published a revised National Framework for CHC and NHS-funded Nursing Care in March 2018, and this will come into force in October 2018. It does not change any of the eligibility criteria, but it is designed to provide greater clarity around assessment process and the role of CCGs and local authorities, as well as to reflect the implementation of the *Care Act 2014.* In particular, aspects of NHS CHC guidance have been amended, including:

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

[38] HM Treasury, *Treasury Minutes: Government response to the Committee of Public Accounts on the Twelfth to the Nineteenth reports from Session 2017-19*, Cm 9596, March 2018, paras 1-5.3, pp14-16

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 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.[39]

5.6 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 out of a 2013 inquiry on NHS CHC 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 CHC 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

[39] Department of Health & Social care, *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care: October 2018 (Revised)*, March 2018, p3

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 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.[40]

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.[41]

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40 Parkinson's UK and Continuing Healthcare Alliance, *Continuing to care? Is NHS continuing healthcare supporting the people who need it in England?*, November 2016, p4

41 *Ibid*., p28

6. NHS continuing healthcare in other parts of the UK

Wales

'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 CHC 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 for CHC, and to provide appropriate care for adults. The most recent revision of the National Framework was completed on 29 June 2014.[42]

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.[43] 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.[44]

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

Northern Ireland

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

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42 Welsh Government, *Continuing NHS Healthcare The National Framework for Implementation in Wales* (June 2014)
43 Scottish Government, *Independent Review of NHS Continuing Healthcare*, May 2014
44 Scottish Government, *Hospital Based Complex Clinical Care* Guidance, May 2015, pp2-6
45 *Ibid.*, p2

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.[46]

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. 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.

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* – published in 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".[47]

In response to this, the Department carried out a comprehensive review which came to the following findings:

- There is confusion about continuing healthcare and its applicability in Northern Ireland. Specifically, there is a lack of understanding that the Checklist Tool and Decision Making Tool used by authorities in England to assess and determine eligibility for continuing healthcare do not apply here and are not part of our existing assessment process.
- It would appear that one of the key drivers for HSC Trusts receiving a request for a continuing healthcare assessment is once an individual needs to, or has, moved into a nursing home. In such circumstances the individual is required to contribute to the cost of their care according to their financial means, for as long as they are able to do so.

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46 Department of Health, *Social Services and Public Safety, Care Management, Provision of Services and Charging Guidance*, 11 March 2010, p5.

47 Age NI, *The Denial of NHS Continuing Health in Northern Ireland*, May 2014, p28

- There is an apparent variance in the application of Departmental guidance and in continuing healthcare practice across the HSC Trusts. This leads to regional inconsistency and a potential 'postcode lottery' for individuals.
- HSC Trusts have indicated that they have found it challenging to apply Departmental guidance.
- Multi disciplinary panels established by the HSC Trusts responsible for making a determination on continuing healthcare applications have found the decision making process extremely difficult; indeed, some HSC Trusts have opted to temporarily suspend the multi disciplinary panels, pending the outcome of the Department's review.
- All HSC Trusts confirmed that individuals are assessed using the Single Assessment Tool (NISAT) Northern Ireland Single Assessment Tool (NISAT), which is the standardised, multi-professional assessment tool providing a framework for holistic, person-centred assessment. HSC Trusts also confirmed that a Nursing Needs Assessment Nursing Needs Assessment Tool (NNAT) (NNAT) is undertaken when required.
- HSC Trusts informed the Department that there are 43 individuals who have been assessed as eligible for continuing healthcare in Northern Ireland (between the periods April 2011 to September 2016). The Department acknowledges that this figure is much lower than corresponding numbers qualifying for continuing healthcare in England, Scotland and Wales. However, it is important to note that the figure here **does not** include those individuals who may meet continuing healthcare eligibility criteria, but receive a care package in their own home for which there is no charge and therefore there is no requirement for the individual to be assessed for continuing healthcare.[48]

As a direct response to these findings, the Department identified four potential options:

- Option 1: Do Nothing
- Option 2: Introduce a Continuing Healthcare Decision Support Tool Model
- Option 3: Introduce a Single Eligibility Criteria Question
- Option 4: Develop Standalone Guidance and assessment Checklist Specific to the HSC System in Northern Ireland.[49]

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

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48 Northern Ireland Department of Health, *Continuing Healthcare in Northern Ireland: Introducing a Transparent and Fair System: Consultation Document*, June 2017, pp4-5

49 *Ibid*., pp6-11

7. Key guidance documents

The following Department of Health 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 November 2012): This sets out principles and processes for establishing eligibility.
- National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care: October 2018 (Revised) (published in March 2018): This is the version of the National Framework which will be in operation from October 2018.
- NHS continuing healthcare checklist (November 2012): This is a screening tool to help establish who might need a full assessment of eligibility.
- NHS continuing healthcare: checklist from October 2018, (published March 2018)
- Decision support tool for NHS continuing healthcare (June 2016 revised): This is a detailed questionnaire to help assess eligibility.
- NHS Continuing Healthcare Decision Support Tool from October 2018 (published March 2018)
- Fast track pathway tool for NHS continuing healthcare (November 2012 revised): This is for urgent assessments of those with rapidly deteriorating, possibly terminal, conditions.
- Fast Track Pathway Tool for NHS Continuing Healthcare from October 2018, (published March 2018)
- NHS-funded nursing care best practice guidance (revised) (July 2013)
- National framework for NHS continuing healthcare and NHS-funded nursing care: equality analysis (March 2013)
- Delayed discharges directions (continuing care) directions (November 2013)

There are several introductory sources that constituents may find useful, for example:

- Department of Health Public Information Leaflet: NHS Continuing Healthcare and NHS Funded Nursing Care (April 2013)
- NHS website: NHS Continuing Healthcare
- Age UK, Factsheet 20, NHS continuing healthcare and NHS-funded nursing care (November 2017)
- Alzheimer's Society, When does the NHS pay for care? Guidance on eligibility for NHS continuing healthcare funding in England, (revised October 2017)

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