Investigation into NHS continuing healthcare funding
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Investigation into NHS continuing healthcare funding

Report by the Comptroller and Auditor General

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Sir Amyas Morse KCB
Comptroller and Auditor General
National Audit Office
28 June 2017
This investigation sets out the facts relating to NHS continuing healthcare (CHC) funding and, in particular, access to CHC funding.

Investigations
We conduct investigations to establish the underlying facts in circumstances where concerns have been raised with us, or in response to intelligence that we have gathered through our wider work.
Contents

Key information 4
What this investigation is about 6
Key findings 8
Part One
Background 12
Part Two
The length of the assessment process 18
Part Three
Access to funding 21
Part Four
The cost 27
Part Five
Variation in access to CHC funding 31
Part Six
Oversight and monitoring of access 35

Appendix One
Our investigative approach 38
Appendix Two
The main concerns raised by correspondents 40
Appendix Three
CHC data 43

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Key information

What this report is about

This report sets out the facts relating to NHS continuing healthcare (CHC) and, in particular, access to CHC funding

The CHC process

For most people the assessment process for CHC funding involves two stages

<table>
<thead>
<tr>
<th>The patient</th>
<th>Initial screening</th>
<th>Full assessment</th>
<th>CHC funding</th>
</tr>
</thead>
<tbody>
<tr>
<td>124,000</td>
<td>77,000</td>
<td>22,000</td>
<td></td>
</tr>
<tr>
<td>83,000</td>
<td></td>
<td>79,000</td>
<td></td>
</tr>
</tbody>
</table>

NHS England recognises that the current assessment process raises people’s expectations about whether they will receive funding and does not make best use of assessment staff

Who’s responsible for what?

- **Department of Health**: the CHC legal framework, including setting criteria for assessing eligibility
- **CCGs**: determining eligibility for CHC and commissioning this care
- **NHS England**: making sure that CCGs comply with the national framework for CHC

Notes

1. All numbers and percentages are for 2015-16 unless stated otherwise. Numbers for the CHC process are rounded to the nearest 1,000.
2. These figures are estimates.

Source: National Audit Office
Investigation into NHS continuing healthcare funding

Key information

What this report is about
This report sets out the facts relating to NHS continuing healthcare (CHC) and, in particular, access to CHC funding.

Notes
1. All numbers and percentages are for 2015-16 unless stated otherwise. Numbers for the CHC process are rounded to the nearest 1,000.
2. These figures are estimates.

Source: National Audit Office

For most people the assessment process for CHC funding involves two stages:

- **Initial screening**: 77,000
- **Full assessment**: 22,000

**CHC funding**

- Estimated percentage of screenings that led to a full assessment: 62%

NHS England recognises that the current assessment process raises people’s expectations about whether they will receive funding and does not make best use of assessment staff.

There is significant variation between CCGs in both the number and proportion of people assessed as eligible for CHC:

- **Variation in access to CHC**: 28 to 356 per 50,000 population
- **Variation in the estimated proportion of people that were referred and subsequently assessed as eligible**: 41% to 86%

There are limited assurance processes in place to ensure that eligibility decisions are consistent, both between and within CCGs:

- Health and social care professionals must use their professional judgement at both the initial screening and full assessment stages.
- There are limited mechanisms for ensuring that individual eligibility decisions are being made consistently across CCGs.
- There is a shortage of data on CHC, for example, on appeals to CCGs about eligibility decisions.

NHS England and the Department of Health have recently started work aimed at providing more consistent access and supporting CCGs to make efficiency savings. From April 2017, it expanded the data it collects on CHC.

The cost of CHC

The funding of CHC is a significant cost pressure on CCGs’ spending.

- CCGs are legally required to provide CHC funding for all those assessed as eligible.
- **16%** Increase in spending on CHC between 2013-14 and 2015-16.
- **4%** Percentage of CCGs’ total spend accounted for by CHC.
- **£5,247m** Expected spend on CHC, NHS-funded nursing care and assessment costs by 2020-21 if no action is taken (£3,607m in 2015-16).
- **£855m** NHS England’s expected savings from reducing administration assessment costs and the overall cost of care.
What this investigation is about

1 NHS continuing healthcare (CHC) is a package of care provided outside of hospital that is arranged and funded solely by the NHS for individuals aged 18 years and older who have significant ongoing healthcare needs. When someone is assessed as eligible for CHC, the NHS is responsible for funding the full package of health and social care. 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. In 2015-16, almost 160,000 people received, or were assessed as eligible for, CHC funding during the year, at a cost of £3.1 billion.

2 Funding for ongoing healthcare is a complex and highly sensitive area, which can affect some of the most vulnerable people in society and those that care for them. If someone is not eligible for CHC, they may have to pay for all or part of their social care costs. Social care services, such as care home fees, may be paid for by local authorities, but the person may need to pay a charge depending on their income, savings and capital assets. Therefore, decisions about whether someone is eligible for CHC may have a significant impact on their finances.

3 The national framework for CHC states that eligibility should be based on someone’s healthcare needs and not their diagnosis. Many people that are assessed for CHC funding are reaching the end of their lives or face a long-term condition, because of a disability, accident or illness. They can have a wide range of healthcare conditions and may receive funding for just a few weeks or many years (Figure 1).

4 The Department of Health (the Department) is responsible for the legal framework for CHC. This includes: setting criteria for assessing eligibility for CHC through a national framework and providing supporting guidance; publishing screening (checklist) and assessment tools; and setting principles for resolving disputes. Clinical commissioning groups (CCGs) are responsible for determining eligibility for CHC and NHS-funded nursing care (for those not eligible for CHC but assessed as needing care from a registered nurse) and for funding and commissioning this care if patients are assessed as eligible. The CCG is legally required to provide CHC funding for all those assessed as eligible. NHS England is responsible for making sure that CCGs comply with the national framework and may arrange independent reviews of CHC decisions if requested by patients.

5 Between February 2016 and July 2017, we have received correspondence from over 100 members of the public raising concerns about the CHC process in England. The correspondents raised a range of concerns covering how well the assessments are carried out, whether CCGs are complying with the national framework and the equity of the decisions, delays in the assessment and appeals processes, and poor communication with patients and their families. Appendix Two summarises the most common concerns raised by correspondents.
This investigation sets out the facts relating to CHC and, in particular, access to CHC funding. It covers:

- who is eligible for CHC funding and what the assessment process is;
- how long the assessment and decision-making process takes;
- access to CHC funding;
- the cost of CHC to the NHS;
- variation in access to CHC funding; and
- the Department’s and NHS England’s arrangements for reviewing access to CHC funding.

Our investigation did not examine individual decisions on eligibility or the delivery of CHC-funded services.
**Key findings**

1. For most people the assessment process for NHS continuing healthcare (CHC) funding involves two stages (paragraphs 1.5, 1.6, and 3.5, and Figures 3 and 4).

   - National data on the total number of people who started the process for CHC funding are not available. However, NHS England estimates that at least 207,000 people started the process for CHC funding in 2015-16.
   - The national framework for CHC states that for most people the assessment process involves an initial screening stage. This uses a CHC checklist to identify people who might need a full assessment.
   - The full assessment should usually be carried out by a group of professionals from across health and social care (known as a multidisciplinary team) who are familiar with the individual’s care needs.
   - There is also a fast-track process, which does not require a full assessment, for individuals with rapidly deteriorating conditions who may be nearing the end of their life. This uses the fast-track pathway tool to determine whether people are eligible.
   - Health and social care professionals must use their professional judgement at both the screening and full assessment stages. They assess the person’s combined healthcare needs across 11 domains in the checklist and 12 domains in the full assessment.

2. NHS England recognises that 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 (paragraphs 3.5 and 3.6).

   - NHS England estimates that at least 124,000 standard (non fast-track) screenings and 83,000 fast-track tools were completed in 2015-16.
   - NHS England estimates that around 62% of people who were screened using the checklist went on to have a full assessment in 2015-16.
   - Clinical commissioning groups (CCGs) reported that approximately 29% of people who were referred for a full assessment were assessed as eligible for CHC in 2015-16.
   - Therefore, overall, NHS England estimates that only about 18% of screenings undertaken led to the person being assessed as eligible for CHC in 2015-16.

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1 NHS England estimates are based on a one-off data collection from CCGs.
3 In most cases eligibility decisions should be made within 28 days but many people are waiting longer (paragraphs 2.1 to 2.5).

- The national framework states that in most cases people should not wait more than 28 days for a decision about whether they are eligible for CHC, following the CCG receiving a completed checklist.

- In 2015-16, about one-third of full assessments (24,901 assessments) took longer than 28 days.

- Approximately 10% of CCGs reported that full assessments took more than 100 days on average between November 2015 and October 2016 (out of 115 CCGs that provided data requested by the Continuing Healthcare Alliance).

- Delays can cause considerable distress to patients and their families as they wait for funding decisions, and in some cases have resulted in delays in discharging patients from hospital.

4 Decisions on eligibility for CHC have a significant financial impact on the individual, clinical commissioning group and local authority (paragraphs 1.2, 1.3 and 3.7).

- During 2015-16, nearly 101,000 people were assessed as newly eligible for CHC, of which 79,000 were referred through the fast-track process.

- During 2015-16, approximately 59,000 people referred through the fast-track or standard CHC process were considered not eligible.

- If someone is assessed as eligible for CHC their health and social care costs are paid for by the CCG. But if they are assessed as not eligible, the local authority and/or the individual may have to pay their social care costs instead.

- If a person is assessed as eligible for CHC funding, the CCG must legally provide that funding, irrespective of the number of people that apply and are assessed as eligible.

5 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 (paragraphs 3.1 to 3.3 and 3.7).

- The population of people receiving CHC funding changes during the year as some people are newly assessed as eligible, some are reassessed and considered no longer eligible, and many patients die, particularly those assessed through the fast-track process.

- Between 2011-12 and 2015-16, the total number of people that received, or were eligible to receive, CHC funding at some point during that year increased from 125,000 to 160,000.

- NHS England’s snapshot data shows that on 31 March 2016, 59,000 were receiving, or assessed as eligible to receive, CHC funding, compared with 63,000 people on 31 March 2015.
- There are no data to track how long people receive CHC funding for, but the above trends indicate that since March 2015, people have received funding for shorter periods. The Department does not have data on the reasons for this changing trend. It may indicate that people tend to apply for, or be assessed as eligible for, CHC funding at a later stage of their illness, or that more people are found to no longer be eligible when they are reassessed.

- Between 2011-12 and 2015-16, the estimated proportion of people referred for a full assessment that resulted in that person being assessed as eligible for standard CHC during that year fell from 34% to 29%.

6 The funding of CHC is a significant cost pressure on CCGs’ spending (paragraphs 3.3, 4.1, 4.2, 4.5 and 4.6).

- The costs of CHC are met by CCGs, from their overall funding allocation from NHS England. Between 2013-14 and 2015-16, spending on CHC increased by 16%.

- In 2015-16, CHC accounted for about 4% of CCGs’ total spending.

- NHS England estimates that spending on CHC, NHS-funded nursing care and assessment costs will increase from £3,607 million in 2015-16 to £5,247 million in 2020-21, when historical growth and population demands are applied to previous CCG spending.

- Although the Department assures us that there is no quota or cap on access, NHS England’s efficiency plan includes asking CCGs to make £855 million of savings on CHC and NHS-funded nursing care by 2020-21 against the above prediction of growth. Savings may be made by reducing the administrative assessment costs (total spend of £149 million in 2015-16) or by reducing the overall cost of care.

- NHS England has not yet set out a costed breakdown for how it will achieve the savings to the cost of care, but it intends to reduce variation in spending and ensure that CCGs interpret the eligibility criteria more consistently. 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 overall compared with NHS England’s predicted growth in eligibility. It assumes that it will also make savings through better commissioning of care packages.

7 It is not known how many people appeal against unsuccessful CHC funding decisions (paragraphs 1.11 and 3.8).

- If a patient is unhappy with the outcome of their assessment they can ask the CCG to review their case, but NHS England does not collect data on how many appeals are made to CCGs, how long they take or how many are successful.

- In 2015-16, 448 cases were reviewed by an independent review panel, because the patient was unhappy with the outcome of the CCG’s own review. In 27% of cases, NHS England recommended a different eligibility decision for part or all of the period reviewed.

- In 2015-16, the Parliamentary and Health Service Ombudsman received 1,250 complaints about CHC funding decisions. It investigated 181 of them and partly or fully upheld 36 cases.
8 There is significant variation between CCGs in both the number and proportion of people assessed as eligible for CHC (paragraphs 5.1 and 5.2).

- In 2015-16, the number of people that received, or were assessed as eligible for, funding ranged from 28 to 356 people per 50,000 population.

- In 2015-16, 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.

- NHS England’s analysis of population data at a CCG level shows that the variation cannot be fully explained by local demographics or other factors it has considered so far. This suggests that 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.

9 There are limited assurance processes in place to ensure that eligibility decisions are consistent, both between and within CCGs (paragraphs 6.1 to 6.6).

- NHS England’s assurance mechanisms for CHC include quarterly reporting and self-assessment by CCGs, overseen by NHS England’s Directorate of Operations and Information and regional assurance boards. However, there are limited mechanisms for ensuring that individual eligibility decisions are being made consistently across CCGs.

- There is a shortage of data on CHC, which makes it difficult to know whether eligibility decisions are being made fairly and consistently.

- NHS England and the Department have recently started work aimed at providing more consistent access to CHC funding and supporting CCGs to make efficiency savings. From April 2017, NHS England has expanded the data it publishes on CHC (see Appendix Three on CHC data).
Part One

Background

What is NHS continuing healthcare?

1.1 NHS continuing healthcare (CHC) is a package of care, usually provided outside of hospital, for individuals aged 18 years and older who have been assessed as having a ‘primary health need’. People who are assessed for CHC funding include some of the most vulnerable in society. Some are reaching the end of their lives, or have long-term conditions as a result of a disability, accident or illness.

1.2 If someone is assessed as eligible for CHC funding, the NHS funds the full package of health and social care. For example, if a patient is eligible for CHC in their own home, the NHS will pay for healthcare costs (such as services from a community nurse or specialist therapist) and for associated social care costs (such as personal care and help with bathing). In a care home, the NHS also pays for people’s care home fees, including board and accommodation.

1.3 If someone is assessed as not eligible for CHC, they may still be entitled to other health and social care services, such as NHS-funded nursing care or social care services funded by the local authority (Figure 2). However, social care services are means-tested, meaning the person may have to pay a charge depending on their income, savings and capital assets. For NHS-funded nursing care, the NHS pays a flat-rate contribution towards the cost of the person’s nursing care (a standard rate of £155 a week in 2017-18). In 2015-16, the average cost of providing care to each person was £19,190 for CHC, compared with £3,305 for NHS-funded nursing care and £9,944 for social care. People that are assessed for CHC often have both health and social care needs, and CHC assessments determine whether the NHS should pay for all of their care. Eligibility decisions can therefore have a significant impact on the finances of the individual, as well as the NHS and local authority.

2 We estimated the average cost by dividing the total cost by the number of people that received, or were assessed as eligible for, funding during the year. The figure represents the average cost per person for an episode of care and is therefore affected by how long people are eligible for funding. We estimated the average cost of providing CHC funding for a year in 2015-16 to be £50,000, while the average cost of providing NHS-funded nursing care was £3,824 for those on a standard rate and £8,015 for those on the higher rate.
### Figure 2
Funding packages for out-of-hospital care

<table>
<thead>
<tr>
<th>Package of care</th>
<th>Source of funding</th>
<th>Services provided</th>
<th>Eligibility criteria</th>
<th>Number of people that received, or were assessed as eligible for, funding in 2015-16</th>
<th>Average cost per person, 2015-16</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continuing healthcare (CHC)</td>
<td>CCGs (fully funded)</td>
<td>An ongoing package of care covering health and social care services as required by the individual.</td>
<td>Primary health need as defined by the national framework.</td>
<td>160,000</td>
<td>£19,190</td>
</tr>
<tr>
<td>NHS-funded nursing care</td>
<td>CCGs (flat-rate contribution)</td>
<td>Services provided by a registered nurse, involving the provision of care or the planning, supervision or delegation of the provision of care. The services can only be provided in a home with nursing care.</td>
<td>Assessment against the CHC checklist and found to have nursing care needs but not a primary health need.</td>
<td>146,000</td>
<td>£3,305</td>
</tr>
<tr>
<td>Joint packages of care</td>
<td>CCGs (contribution) and local authorities (means-tested)</td>
<td>A combination of social care as well as some nursing and health services that the local authority does not have the legal powers to provide.</td>
<td>Based on the assessed needs of the person and the limits of what a local authority can fund. The CCG and local authority may negotiate the costs of the jointly funded package if a person is assessed as not eligible for CHC.</td>
<td>13,000</td>
<td>Not known</td>
</tr>
<tr>
<td>Adult social care</td>
<td>Local authorities (means-tested)</td>
<td>Home adaptations and equipment, residential care, community support and carers to help with personal care such as washing and dressing.</td>
<td>Determined by the criteria set out in the Care Act 2014.</td>
<td>1,108,000</td>
<td>£9,944</td>
</tr>
</tbody>
</table>

**Note**
1. The adult social care figures are estimated using NHS Digital data on Personal Social Services Expenditure and Community Care Statistics. Expenditure includes all types of long- and short-term support. There is a small degree of double counting in the number of people supported during the year as some people may have more than one episode of support. Only short-term episodes of support categorised as ‘support to maximise independence’ are included.

Source: National Audit Office
Eligibility for CHC

1.4 There is no legal definition of what constitutes a ‘primary health need’. However, a key court judgment, known as the Coughlan case, set a precedent for when someone’s healthcare needs are beyond the responsibilities of local authorities and should be paid for by the NHS. Details of the case are set out in the National framework for CHC and NHS-funded nursing care. It led to the clarification in the legal framework that local authorities can legally provide health services, such as nursing care, but only if they are incidental or ancillary to the social care being provided and are of a nature that the local authority can be expected to provide. Therefore, for any individual with healthcare needs over and above this level, the NHS is responsible for providing and funding the services required.

1.5 Health and social care professionals need to use their clinical judgement to assess whether they think someone is eligible for CHC funding against the national framework. This states that, as a general rule, someone has a primary health need if the main aspects or majority part of their care are focused on addressing health needs or preventing them from developing. It describes four characteristics of need to help health and social care professionals determine whether an individual’s healthcare requirements are above the legal limits of what a local authority can provide following the Coughlan case. These are the nature, intensity, complexity and unpredictability of the need. However, health and social care professionals must use their professional judgement to determine the totality of needs across 12 care domains (Figure 3).

The assessment process for CHC

1.6 Figure 4 (on page 16) shows the assessment process for CHC funding. For most people, this involves an initial screening stage that uses the CHC checklist to identify people who might need a full assessment. In most cases, the full assessment should be carried out by a group of professionals usually from across health and social care (known as a multidisciplinary team) who are familiar with the individual’s care needs. The multidisciplinary team makes a recommendation to the clinical commissioning group (CCG) about whether the person is eligible and the CCG makes the final decision on CHC eligibility. However, CCGs are required to consult with the local authority, as far as is reasonably practicable, before making a decision on a person’s eligibility and local authorities are required to provide advice and assistance to CCGs. In some cases, the CCG carries out the assessment, but in others it commissions a commissioning support unit, local authority or other organisation to carry out the assessment.

3 This clarification is reflected in the Care Act 2014 and regulations under the NHS Act.
4 Department of Health, National framework for NHS continuing healthcare and NHS-funded nursing care, November 2012 (revised).
Organisations that represent patients who have been assessed for CHC funding, such as the Continuing Healthcare Alliance, told us they had concerns about the quality of the multidisciplinary team assessment. They said that the assessment is not always carried out by a multidisciplinary team or by people who have a knowledge of the person or the condition that is being assessed. The correspondents who wrote to us raised similar concerns. They also reported that the individual and their representative were not always invited to, or adequately involved in, the assessment (Appendix Two).

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**Figure 3**
Framework for assessing someone’s combined health needs

<table>
<thead>
<tr>
<th>Care domains or areas of need</th>
<th>Checklist tool descriptions</th>
<th>Decision support tool descriptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Behaviour</td>
<td>There are three checklist descriptions:</td>
<td>There are six assessment descriptions:</td>
</tr>
<tr>
<td>2 Cognition</td>
<td>- no or low needs;</td>
<td>1 = no needs;</td>
</tr>
<tr>
<td>3 Psychological and emotional needs</td>
<td>- moderate needs; and</td>
<td>2 = low needs;</td>
</tr>
<tr>
<td>4 Communication</td>
<td>- high needs.</td>
<td>3 = moderate needs;</td>
</tr>
<tr>
<td>5 Mobility</td>
<td>A full assessment is required if the checklist shows:</td>
<td>4 = high needs;</td>
</tr>
<tr>
<td>6 Nutrition – food and drink</td>
<td>- two or more domains are rated as high;</td>
<td>5 = severe needs;* and</td>
</tr>
<tr>
<td>7 Continence</td>
<td>- five or more domains are rated as moderate;</td>
<td>6 = priority needs.*</td>
</tr>
<tr>
<td>8 Skin including tissue viability</td>
<td>- one domain rated as high and four as moderate; or</td>
<td>* Does not apply to some of the care domains.</td>
</tr>
<tr>
<td>9 Breathing</td>
<td>- a high rating in any of the domains with a priority level (in the decision support tool) plus any level of need in the other domains.</td>
<td>The assessment team should also use the four key characteristics of need (nature, intensity, complexity and unpredictability), wherever relevant. Each of the four key indicators may alone, or in combination, indicate a primary health need. The team should use their professional judgement to consider the totality of need identified across the domains and indicators. A recommendation of eligibility would be expected if the patient has:</td>
</tr>
<tr>
<td>10 Drug therapies and medication: symptom control</td>
<td>- a priority level of need in any of the four domains where it is possible to have a priority need; or</td>
<td></td>
</tr>
<tr>
<td>11 Altered states of consciousness</td>
<td>- there is one domain recorded as severe together with needs in a number of other domains where it is possible to have a priority need; or</td>
<td>A primary health need may also be indicated if:</td>
</tr>
<tr>
<td>12 Other significant care needs that need to be taken into consideration</td>
<td>- a number of domains with high/ moderate needs.</td>
<td></td>
</tr>
</tbody>
</table>

Notes
1. Care domains 1 to 11 are assessed as part of the checklist tool, and all 12 are assessed as part of the decision support tool assessment.
2. The checklist tool is used at an initial screening stage and the decision support tool is used at the full assessment.

Source: National Audit Office
Figure 4
The assessment process for CHC

- **Individual may be eligible for CHC**
  - Has the individual been identified as having a rapidly deteriorating condition, that may be entering a terminal phase?
  - **No**
  - **Yes**
    - **Health or social care staff arrange services and then review progress**

- **Fast-track applications**
  - Yes
  - **Completion of fast-track tool by an appropriate clinician**
  - **Recommendation sent to clinical commissioning group (CCG), which should accept and take immediate action to arrange for the provision of CHC**

- **Checklist completed and criteria for a full assessment are met?**
  - **No**
    - The individual can ask the CCG to reconsider its decision. If the decision remains the same, the individual has the right to access the NHS complaints procedure which consists of a written complaint to the CCG complaint manager and then the option to refer the complaint to the Parliamentary and Health Service Ombudsman.
  - **Yes**
    - **Individual completing the checklist contacts the CCG which arranges for a multidisciplinary team to carry out a full assessment of the individual’s needs using the decision support tool**

- **Team recommends that the CCG provides CHC funding?**
  - **No**
    - Health and social care staff consider whether the person meets the eligibility criteria for NHS-funded nursing care or joint packages of care.
  - **Yes**
    - **Recommendation accepted by the CCG except in exceptional circumstances, such as when the tool has not been completed fully, and when there are gaps in the evidence or an obvious mismatch between the evidence and the recommendation**

- **Review of needs after three months and then at least every year. For individuals who have been fast-tracked, the CCG may arrange for a review of needs and arrange a decision support tool to be completed after immediate support has been provided following the completion of a fast-track tool**

- **Assessment process for CHC or other packages of care**
- **Appeals and complaints process**

Source: National Audit Office
1.8 The national framework states that every person receiving CHC funding should have their case reviewed three months after their initial assessment, and at least annually thereafter, to assess whether they are still eligible for CHC.

1.9 There is a fast-track process for individuals with rapidly deteriorating conditions who may be nearing the end of their life. A suitable clinician uses the fast-track pathway tool to determine whether people are eligible and if so, makes a recommendation to the CCG to provide funding.

1.10 People can also submit a request for unassessed periods of care where they believe that they, or a family member, should have been eligible for CHC in the past but were not assessed for CHC and paid for their own care. In March 2012, the Secretary of State for Health announced a deadline of 30 September 2012 for individuals to notify their relevant authority if they believed that they or a family member had been eligible for CHC between 1 April 2004 and 31 March 2011 but had not been assessed. Another deadline of 31 March 2013 was set for individuals to notify their relevant authority if they believed they were eligible between 1 April 2011 and 31 March 2012. CCGs were expected to process the backlog of requests by 31 March 2017. NHS England told us that by the end of January 2017, all these cases had been assessed. People can also submit claims for unassessed periods of care that occurred after 31 March 2012.

**Appeals and complaints**

1.11 There are three stages to the appeals process:

- If a patient is unhappy with the outcome of the CCG’s eligibility decision they can ask the CCG to review their case. This process can vary locally as this is not prescribed in the national framework and each CCG sets its own processes and timescales.

- If a patient is unhappy with the outcome of the CCG’s review of their case, they can ask NHS England for an independent review, which may be carried out by one of the four NHS England regions.

- If a patient is unhappy with the outcome of the independent review, they can complain to the Parliamentary and Health Service Ombudsman. The ombudsman’s role is to decide whether decisions made by the NHS are in line with the national framework; it does not generally make judgements about whether the NHS has made the right decision. NHS England has taken on board feedback from the ombudsman, for example by refreshing its CHC redress guidance in 2015.
Part Two

The length of the assessment process

2.1 The national framework states that in most cases, clinical commissioning groups (CCGs) should make a decision about whether someone is eligible for NHS continuing healthcare (CHC) within 28 days of receiving a completed checklist. In 2015-16, about one-third of full assessments (24,901) took longer than 28 days. Figure 5 shows that both the number and percentage of referrals taking longer than 28 days is increasing.

2.2 Some people are waiting a considerable time for a decision about whether they are eligible. The Continuing Healthcare Alliance asked all 209 CCGs how long assessments took on average between receiving the CHC checklist and informing the family of the decision, for the period November 2015 and October 2016. Of the 115 CCGs that responded with data, half reported that assessments took more than 28 days on average and around 10% reported that assessments took more than 100 days on average. The average time ranged from 3 days to 204 days. A further 90 CCGs reported that they did not collect data on how long it took to carry out an assessment and inform the family of their eligibility decision. For 2017-18 and 2018-19, NHS England introduced a financial incentive to encourage CCGs to complete more than 80% of eligibility decisions within 28 days.

2.3 NHS England does not collect data on the reasons for delays in making CHC eligibility decisions. However, our report Discharging older patients from hospital identified a range of challenges to completing timely CHC assessments in acute hospital settings, including:

- ensuring there were enough sufficiently trained staff to do the assessment;
- ensuring that the assessment was completed correctly – if an assessment is incorrect, it may need to be returned causing delays;

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5 For fast-track recommendations, CCGs should accept these and take immediate action to arrange for provision of CHC funding.
6 The proportion that took longer than 28 days has been estimated by dividing the number of assessments that took longer than 28 days in that year by the number of people who were referred for an assessment in that year. The number that took longer than 28 days may include referrals from the previous year and some referrals for that year might result in delays in the following year.
7 The data were collected from CCGs in November 2016.
8 The financial incentive is awarded through the quality premium programme, which rewards CCGs for improvements to the quality of the services that they commission.
9 Comptroller and Auditor General, Discharging older patients from hospital, Session 2016-17, HC 18, National Audit Office, May 2016.
• managing patients’ and carers’ involvement in and expectations of the process; and

• increased scrutiny of applications, partly due to cost pressures, which meant applications were taking longer.

In January 2017, NHS England wrote to CCGs asking them to put in place a number of actions likely to support timely assessments including daily liaison with hospital discharge teams to identify and address CHC-related delays.

**Figure 5**
The number and percentage of referrals exceeding 28 days, quarter one of 2014-15 to quarter two of 2016-17

The number and percentage of referrals taking longer than 28 days is increasing

**Note**
1 The figures do not include people that were assessed as eligible for CHC for previously unassessed periods of care.

Source: National Audit Office analysis of NHS England data
2.4 NHS England told us that in some CCGs, the need to process assessments for previously unassessed periods of care could have resulted in delays in assessing people’s current eligibility. CCGs received almost 63,000 requests for previously unassessed periods of care following the Secretary of State’s March 2012 announcement that patients and their families could apply for previously unassessed periods between 1 April 2004 and 31 March 2012. Of these, around 28,000 (44%) resulted in a full assessment and around 8,900 (14%) were assessed as eligible or partially eligible. In many of these cases the individual had passed away some time ago. In some cases, these assessments may have taken years to carry out (see Appendix Two).

2.5 The correspondence we received from members of the public showed that delays can cause considerable distress, and in some cases, considerable financial hardship, to patients and their families as they wait for funding decisions. In some cases, people have died while waiting for a decision. For fast-track recommendations, CCGs should accept these and take immediate action to arrange for provision, but there are no national data on how quickly this happens.

2.6 Delays may also occur during the appeals process. The national framework for CHC states that CCGs should deal with challenges in a timely way and publish their timescales for responding. However, no national data are available on the first stage of the appeals process (asking the CCG to review the case) covering how many appeals are made, how long they take and how many are successful. Charities representing patients told us that the quality of individual CCGs’ processes for resolving appeals at this stage is very variable.

2.7 For the second stage of the appeals process, independent review, the length of the process varies depending on a number of factors including: the availability of family members; the availability of NHS and social care representatives; and the length and complexity of the case. At the beginning of April 2017, there were 360 cases ready to proceed to an independent review. NHS England told us that the majority of these cases should have had an independent review within the next six months. However, some patients have reported waiting years to receive an outcome from the appeals process (see Appendix Two).

2.8 Waiting for CHC assessments has also resulted in delays in discharging patients from hospital. In a survey of hospitals we carried out around 70% of the 76 hospitals that responded indicated that CHC assessments had caused major or moderate delays in discharging older patients from hospitals. However, NHS England’s data show that in the first 11 months of 2016-17, 6% of delayed transfers of care in hospital were due to waiting for a variety of assessments, including for CHC.10

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Part Three

Access to funding

3.1 Between 2011-12 and 2015-16, the number of people that received, or were assessed as eligible for, NHS continuing healthcare (CHC) funding during that year increased from 125,000 to 160,000 (Figure 6 overleaf). This represents an average year-on-year increase of 6.4%. Part of this increase is likely to be accounted for by a growing and ageing population living with complex and long-term care needs. Over this period, the population grew by an average of 0.8% a year and the number of people aged over 65 grew by an average of 2.7% a year.

3.2 Despite the growing and ageing population, in snapshot data collected by NHS England, the number of people that were receiving, or assessed as eligible for, CHC funding reduced from 63,000 on 31 March 2015 to 59,000 on 31 March 2016 (Figure 7 on page 23).

3.3 NHS England has no national data to track for how long people receive CHC funding. However, the increasing number of people that received, or were assessed as eligible for, funding during the year compared with the declining number of people given in the snapshot data, suggests that since 31 March 2015, people have received CHC funding for shorter periods. It may indicate people are being assessed, or found eligible for funding, at a later stage of their illness, or because they are reassessed and no longer considered eligible. There has been no change to the national framework for assessing or reassessing eligibility during this period, and NHS England assured us that there was no quota or cap on eligibility or funding.

3.4 Between April 2013 and February 2017, clinical commissioning groups (CCGs) also assessed 8,853 people as eligible, or partially eligible, for previously unassessed periods of care relating to the period from 1 April 2004 to 31 March 2012. This represents 14% of the total number of requests that were received. Between April 2014 and September 2015, CCGs also assessed people for previously unassessed periods of care relating to the period after March 2012. However, NHS England does not have accurate data on either the number of people that requested an assessment, or the number assessed as eligible for this period. NHS England told us that in some CCGs, assessments for previously unassessed periods of care could have resulted in delays in assessing people’s current eligibility.
Figure 6
Number of people that received, or were assessed as eligible for, CHC funding during that year, 2011-12 to 2015-16

The number of people that receive, or are assessed as eligible for, CHC funding is growing by 6.4% a year on average

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of people (000)</th>
<th>Percentage increase</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011-12</td>
<td>124,762</td>
<td>6.9</td>
</tr>
<tr>
<td>2012-13</td>
<td>133,344</td>
<td>6.6</td>
</tr>
<tr>
<td>2013-14</td>
<td>142,150</td>
<td>9.4</td>
</tr>
<tr>
<td>2014-15</td>
<td>155,497</td>
<td>2.6</td>
</tr>
<tr>
<td>2015-16</td>
<td>159,565</td>
<td></td>
</tr>
</tbody>
</table>

Notes
1. The figures do not include people that were assessed as eligible for CHC for previously unassessed periods of care.
2. Primary care trusts and strategic health authorities were responsible for CHC until 31 March 2013, when responsibilities transferred to CCGs and NHS England.
3. In 2013-14, there were issues with the quality of the data while data were migrated from primary care trusts to CCGs and CCGs set up new systems. Some issues with data quality remain with the data currently collected.

Source: National Audit Office analysis of NHS England data
3.5 NHS England has data on how many people are referred for a full assessment for CHC funding, but does not collect on the total number of screenings undertaken. However, NHS England has estimated that at least 124,000 standard (non fast-track) screenings and 83,000 fast-track tools were completed in 2015-16, meaning an estimated 207,000 people started the process for CHC funding.\footnote{The estimated number of screenings has been calculated by taking the number of positive screenings and dividing by NHS England’s estimate of the proportion of screenings that lead to a positive result – 62\% in 2016-17 based on a one-off data collection from CCGs.} It estimates that 62\% of people who received a standard screening went on to have a full assessment. These estimates were based on a one-off data collection from CCGs carried out by NHS England. They are likely to underestimate the number of screenings carried out because CCGs may not receive information where screenings are unsuccessful.
3.6 In 2015-16, CCGs reported that approximately 29% of people who were referred from the screening stage were assessed as eligible for CHC at the full assessment stage. Using this data, NHS England estimates that overall, only about 18% of screenings undertaken in 2015-16 led to the person being assessed as eligible for CHC. The national framework states that the purpose of the screening is to identify people who may need a full assessment for CHC. However, NHS England recognises that the low threshold for a positive referral at the screening stage can raise people’s expectations about their eligibility for CHC as around two-thirds who have a full assessment will not be found eligible. NHS England told us that this low threshold has resourcing implications as multidisciplinary teams spend most of their time carrying out assessments that do not lead to people being assessed as eligible. It also has implications for the appeals process as people assessed as not eligible may wish to appeal.

3.7 During 2015-16, nearly 101,000 people were assessed as newly eligible for CHC, of which 79,000 were referred through the fast-track process. Over this period, approximately 59,000 people referred through the fast-track or standard CHC process were considered not eligible. Overall, the estimated proportion of people assessed as eligible following a referral for standard CHC or a recommendation for fast-track approval increased from 59% in 2011-12 to 63% in 2015-16 (Figure 8).\(^\text{12}\) Contributing to this overall trend, we estimate that:

- The proportion of people assessed as eligible through the fast-track process for patients with rapidly deteriorating conditions who may be nearing the end of their life remained relatively constant, between 93% and 94%.
- The proportion of people referred through the fast-track process increased from 43% to 52% of all referrals (an increase of 30,478 people). In 2015-16, 83,000 people were referred through the fast-track process, of which approximately 79,000 were assessed as eligible.
- The proportion of people assessed as eligible for standard CHC by CCGs reduced from 34% to 29%, representing 1,604 fewer people (Figure 9 on page 26). NHS England does not have data to explain this reduction. The eligibility criteria have not changed, and there has been no changes to the national framework since November 2012.

\(^{12}\) The proportion assessed as eligible has been estimated by dividing the number of people who were assessed as eligible in that year by the number of people who were referred for a full assessment or were fast-track referrals in that year. The number assessed as eligible may include referrals from the previous year and some referrals for that year might not result in an assessment until the following year.
3.8 Organisations representing patients told us that many people that do not agree with the outcome of their assessment do not raise an appeal because they are too distressed to go through the complex appeals process. NHS England does not collect data on the number of decisions that are reviewed and overturned locally. However, in 2015-16, 448 cases were reviewed by an independent review panel, the second stage of the appeals process. In some 122 (27%) of cases, the panel recommended a different eligibility decision for either all or part of the period reviewed. In 2015-16, the Parliamentary and Health Service Ombudsman, the third stage of an appeal, received 1,250 complaints. It investigated 181 of them and partly or fully upheld 36 cases.

**Figure 8**

Estimated proportion of people assessed as eligible for CHC funding, following a referral for standard CHC or a recommendation for fast-track approval, 2011-12 to 2015-16

The overall proportion of people assessed as eligible for CHC has increased slightly

<table>
<thead>
<tr>
<th>Year</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011-12</td>
<td>59</td>
</tr>
<tr>
<td>2012-13</td>
<td>61</td>
</tr>
<tr>
<td>2013-14</td>
<td>62</td>
</tr>
<tr>
<td>2014-15</td>
<td>63</td>
</tr>
<tr>
<td>2015-16</td>
<td>63</td>
</tr>
</tbody>
</table>

Note
1. The figures do not include people that were assessed as eligible for CHC for previously unassessed periods of care.

Source: National Audit Office analysis of NHS England data
Figure 9
The number and estimated proportion of people assessed as eligible for standard (non fast-track) CHC, 2011-12 to 2015-16

The estimated proportion of standard (non fast-track) referrals assessed as eligible for CHC is falling

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of people referred for standard CHC (000)</th>
<th>Number of people assessed as eligible for standard CHC</th>
<th>Estimated proportion of people assessed as eligible for standard CHC (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011-12</td>
<td>70,243</td>
<td>23,950</td>
<td>34</td>
</tr>
<tr>
<td>2012-13</td>
<td>72,615</td>
<td>23,494</td>
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<tr>
<td>2013-14</td>
<td>75,779</td>
<td>24,681</td>
<td>33</td>
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<tr>
<td>2014-15</td>
<td>76,526</td>
<td>23,973</td>
<td>31</td>
</tr>
<tr>
<td>2015-16</td>
<td>76,944</td>
<td>22,346</td>
<td>29</td>
</tr>
</tbody>
</table>

Note
1 The figures do not include people that were assessed as eligible for CHC for previously unassessed periods of care.

Source: National Audit Office analysis of NHS England data
Part Four

The cost

4.1 Between 2013-14 and 2015-16, spending on NHS continuing healthcare (CHC) increased by £415 million (16%) (Figure 10 overleaf). Over the same period, spending on the NHS as a whole increased by around 6% and spending on NHS-funded nursing care remained relatively constant. The number of people that received, or were assessed as eligible for, CHC funding increased by 12% over this period. NHS England does not collect data on the average annualised cost of CHC per person, but we estimated that this cost increased by 9% over the same period, from £45,850 to £50,000.\textsuperscript{13}

4.2 Clinical commissioning groups (CCGs) are responsible for funding CHC, from the overall funding allocation they receive from NHS England. CCGs will set a budget based on what they expect they may need. However, funding is demand-led, and CCGs are legally required to provide funding in all cases where a person has been assessed as eligible for funding. In 2015-16, CHC accounted for about 4% of CCGs’ total spending.

4.3 There is significant variation between CCGs in the amount spent on CHC as a proportion of their total spending, which ranged from 2.0% to 7.1% in 2015-16, excluding the 5% of CCGs with the lowest and highest percentages (Figure 11 overleaf).

4.4 In addition to funding provided directly by CCGs, in 2015-16, NHS England also spent £92 million on CHC funding for previously unassessed periods of care relating to periods before April 2013. During this period, primary care trusts were responsible for providing CHC.

\textsuperscript{13} We estimated this number by dividing the total cost by an average of the total number of people that were currently eligible for CHC at the start and end of the year. The average cost per person is significantly lower, at around £18,190 in 2015-16, as many people receive CHC funding for less than a year.
Figure 10
Spending on CHC and NHS-funded nursing care, 2013-14 to 2015-16

Spending on CHC has increased while spending on NHS-funded nursing care has remained constant

![Figure 10](image_url)

**Notes**
1. The figures include spending on previously unassessed periods of care relating to periods after April 2013. It does not include spending on previously unassessed periods of care in relation to periods before April 2013.
2. Percentages shown are increase in spending compared to previous year.

Source: National Audit Office analysis of NHS England data

Figure 11
Spend on CHC as a proportion of total spend, by CCG, 2015-16

In 2015-16, there was significant variation between CCGs in spend on CHC as a proportion of their total spending

![Figure 11](image_url)

Source: National Audit Office analysis of NHS England data
Pressures on future spending

4.5 NHS England estimates that CCGs’ spending on CHC (excluding personal healthcare budgets\textsuperscript{14}), NHS-funded nursing care and assessment costs will increase by £1.64 billion (45%) from £3.607 billion in 2015-16 to £5.247 billion in 2020-21 if they do not take action to control costs \textbf{(Figure 12)}. The predicted rise in spending is based on historical growth rates and future population demands, applied to historical spending. NHS England plans to deliver £855 million of savings compared with the level of spending if no action were taken, by increasing standardisation, reducing variation between CCGs, and adopting best practice, including in conducting assessments and in procurement. This would mean that spending in 2020-21 would be £4.392 billion. The £855 million saving target was set by NHS England, and CCGs do not have spending plans setting how they propose to achieve these savings against the background of a growing and ageing population.

\textbf{Figure 12}

Target spending on CHC, NHS-funded nursing care and assessment costs compared to spending if no action is taken, 2015-16 to 2020-21

NHS England expects spending to increase to £5,247 million in 2020-21 if no action is taken

\textbf{Note}

1 The above figures on CHC spending do not include spending on personal healthcare budgets for people that are assessed as eligible for CHC.

Source: National Audit Office analysis of NHS England data

\textsuperscript{14} Some people that are assessed as eligible for CHC funding choose to be funded through a personal healthcare budget, which is an amount of money given to someone to allow them to manage their healthcare needs. CCGs spent £38 million on personal healthcare budgets in 2015-16. NHS England have excluded personal health budgets from their estimates of projected spending and plans to deliver £855 million of savings.
4.6 NHS England does not yet have a costed breakdown for how it plans to achieve these savings. Savings may be made by reducing the administrative assessment costs or by reducing the overall cost of care. In 2015-16, £149 million was spent on CHC assessment costs. Regarding any reduction in the overall cost of care, NHS England told us that it did not expect the eligibility for CHC to change, as this is mandated in legislation and reflected in the national framework. Rather, CCGs would look at interpreting these criteria more consistently. NHS England assumes that increasing both consistency and the number of patients assessed after being discharged from hospital will result in CCGs providing CHC funding to fewer patients overall compared with NHS England’s predicted growth in eligibility. It assumes that it will also make savings through better commissioning of care packages.

4.7 The national framework states that financial issues should not be considered as part of the decision about an individual’s eligibility for CHC. It states that CCGs can take account of comparative costs and value for money when commissioning services, but should commission services which reflect the individuals’ preference as far as possible. The care that individuals choose might not always be the lowest cost option meaning there is a potential conflict between choosing a package which reflects the individual’s choice and which provides best value to the taxpayer.

4.8 Part Six looks at how NHS England is overseeing and supporting CCGs, including on making these savings.
Part Five

Variation in access to CHC funding

Local variation

5.1 In 2015-16, there was significant variation between CCGs in eligibility for CHC funding:

- the number of people that received, or were assessed as eligible for, funding ranged from 28 to 356 people per 50,000 population (Figure 13 overleaf); and

- the estimated proportion of people that were referred, for fast-track or who were identified as needing a full assessment, and subsequently assessed as eligible ranged from 41% to 86%, excluding the 5% of CCGs with the lowest and highest percentages (Figure 14 on page 33).

5.2 NHS England cannot fully explain the variation in the number of people assessed as eligible for CHC. Its analysis shows:

- the variation has not been fully explained by the demographics of the population within each catchment area, such as size and age;

- a weak correlation between the location of the assessment and the number assessed as eligible; and

- no quantitative evidence of a relationship with other factors including: the number of acute hospital beds; length of hospital stay; number of hospital emergency bed days; social care spending; community care spending; and number of appeals.

NHS England has not analysed every factor which could affect eligibility as some factors, such as the availability of community services, are difficult to quantify. However, the findings suggest that some of the variation in the numbers assessed as eligible for CHC may be due to differences in the way CCGs and local authorities interpret the national framework to assess whether people are eligible, due to its complexity. We also found a weak negative correlation between the numbers assessed in a CCG and its eligibility rate, with those CCGs receiving the most applications being more likely to have lower eligibility rates. NHS England recognises that more work needs to be done to quantify and explain the variation in access to funding, including how much variation is warranted and unwarranted.
Figure 13
Number of people that received, or were assessed as eligible for, CHC funding per 50,000 population by CCG, 2015-16

There is significant variation between CCGs in the number of people that receive, or are assessed as eligible for, CHC funding per 50,000 population.

Note
1 The figures do not include people that were assessed as eligible for CHC for previously unassessed periods of care.

Source: National Audit Office analysis of NHS England data.
Figure 14
Estimated proportion of people assessed as eligible for CHC funding by CCG, 2015-16

There is significant variation between CCGs in the proportion of people assessed as eligible for CHC funding.

Estimated proportion of people assessed as eligible (%)

Note
1. The figures do not include people that were assessed as eligible for CHC for previously unassessed periods of care.

Source: National Audit Office analysis of NHS England data
5.3 Assessment of eligibility for CHC can take place within or outside of a hospital setting. The national framework notes that it can be difficult to make an accurate assessment of an individual’s needs while they are in an acute hospital environment. Analysis by NHS England indicates a weak correlation between CCGs that carried out more assessments in hospital and those that assessed more people as eligible for CHC. For 2017-18 and 2018-19, NHS England introduced a financial incentive to encourage CCGs to carry out 85% of assessments outside hospital,\(^\text{15}\) as it believes that this gives a better indication of people’s long-term care needs. Of 76 hospitals that responded to a survey for our report *Discharging older patients from hospital*,\(^\text{16}\) 45% said that they were not able to complete the assessment in the patient’s normal place of residence. Stakeholders told us that they generally support the move for more assessments to take place outside of hospital, but raised concerns about who will fund the care before the assessment takes place. They said that the financial incentive may lead to perverse behaviours, for example, patients being placed in care homes in order to get them out of hospital, when the care home may not be the best option for the patient and may end up costing the individual or the state more in the longer term.

\(^\text{15}\) The financial incentive is awarded through the quality premium programme, which rewards CCGs for improvements to the quality of the services that they commission.

\(^\text{16}\) Comptroller and Auditor General, *Discharging older patients from hospital*, Session 2016-17, HC 18, National Audit Office, May 2016.
Part Six

Oversight and monitoring of access

Gaining assurance over clinical commissioning groups’ (CCGs’) processes

6.1 NHS England has a statutory responsibility to undertake annual assessments of CCGs and obtain assurance that they are fulfilling their statutory responsibilities. The assurance mechanisms for CHC include quarterly reporting and self-assessment by CCGs, overseen by regional assurance boards, that meet to discuss current CHC cases and NHS England’s Directorate of Operations and Information, that meet on an exceptions basis, such as when performance issues are identified. NHS England’s regional teams may then undertake more detailed pieces of work examining the performance issues identified in a particular CCG.

6.2 NHS England currently has limited mechanisms to ensure that individual eligibility decisions are being made fairly and consistently both between and within CCGs. In Wales, the Welsh Government in conjunction with NHS Wales carries out an annual sample audit to determine whether the eligibility decisions are being made fairly and consistently across health boards (Figure 15 overleaf).

6.3 Data are important for evaluating whether the assessment process for CHC is consistent with the requirements of the national framework. NHS England acknowledges that:

- There is a shortage of data on the CHC process. Appendix Three shows the data that are not available on CHC, which includes how long people wait for the initial screening, how long full assessments take on average and the number and outcome of appeals that are made locally.

- There are a number of issues with the quality of the data it currently collects. For example, NHS England told us that some CCGs are using an incorrect start date when reporting the number of CHC assessments that took longer than 28 days. Some CCGs may be incorrectly excluding stages of the assessment from the 28-day time frame if there are delays outside their control, such as when the family postpones the assessment.
6.4 From 1 April 2017, NHS England expanded the data it publishes on CHC to help address some of these gaps and improve data quality. The data set now includes:

- the number of referrals received and the number that lead to full assessments;
- the number of referrals that are assessed as eligible and not eligible;
- more detailed information on cases exceeding 28 days (CCGs will also be asked to investigate the reasons why some cases take longer than 28 days); and
- the number of assessments in acute hospital settings.

<table>
<thead>
<tr>
<th>Organisational self-assessment</th>
<th>Wales</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Health boards carry out annual self-assessments using the tool issued by the Wales Audit Office.</td>
<td>CCGs should use audit tools to check processes and quality at different stages, but the national framework does not specify how frequently this should be done. NHS England assurance leads have access to the tool and can check if it is being done to a sufficient standard.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reporting arrangements</th>
<th>Wales</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Each health board director should present a quarterly performance report. The Welsh Government collates a publicly available national report.</td>
<td>Quarterly reports are published showing eligibility data by CCG. NHS England collects other benchmarking data, such as cases exceeding 28 days, but these are not published. In 2015-16, it published data packs showing how CCGs compare in terms of eligibility.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Annual sample audit</th>
<th>Wales</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Welsh Government in conjunction with NHS Wales conducts an annual sample audit to determine whether the eligibility decisions are being made fairly and consistently across health boards.</td>
<td>No equivalent process.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Service-user feedback</th>
<th>Wales</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>The performance framework commits to developing service user feedback. The Welsh Government is considering options for how to do this.</td>
<td>Beacon is an independent social enterprise which provides private advocacy services to individuals in England in the area of CHC. It also receives funding from NHS England to provide information and advice. As part of this contract, it collects information from patients who contact it and anonymously feeds back trends and challenges to NHS England.</td>
<td></td>
</tr>
</tbody>
</table>

Note 1 Beacon is a social enterprise that evolved from a service provided by Age UK Oxfordshire.

Source: National Audit Office
The CHC strategic improvement programme

6.5 In 2016, NHS England and the Department of Health (the Department) began scoping work aimed at providing fairer access to CHC funding and identifying opportunities for efficiency savings to help close the widening gap between NHS resources and overall patient needs. This led to a NHS England target to reduce growth in CHC spending (see paragraph 4.5). An NHS England document setting out its early thinking on where savings could be made included reducing the number of people eligible for CHC and reducing the average cost of the CHC package. Figure 16 shows some areas where the Department and NHS England now expect CCGs can deliver CHC savings. NHS England has established a strategic improvement programme aimed at providing fairer access to CHC in a way which ensures better outcomes, better experience and better use of resources. The programme includes workstreams to develop and test best practice involving 26 CCGs, and to share learning more widely across CCGs. NHS England also runs regular webinars to encourage CCG engagement and knowledge sharing.

6.6 The Department has been working with NHS England, local authority representatives and charity groups to understand the impact of the national framework on delivery of CHC and where there might be scope for improvements.

<table>
<thead>
<tr>
<th>Initiative</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improving CHC processes</td>
<td>NHS England wants 85% of patients to be assessed outside hospital, so that their recovery is maximised by the time they are assessed. The initiative also includes implementing a more consistent and streamlined CHC process, from the initial screening to the commissioning of care.</td>
</tr>
<tr>
<td>Implementing an electronic procurement system</td>
<td>This might include using collaborative purchasing systems, which may reduce expenditure due to economies of scale.</td>
</tr>
<tr>
<td>Investing in CHC workforce skills and capacity</td>
<td>This includes investing in recruitment, training and retention to improve CHC commissioning capability and capacity.</td>
</tr>
<tr>
<td>Increasing case management for existing care packages</td>
<td>Ongoing case management to ensure that patients receive the right care at the right time. If a patient's care needs lessen, this would be reflected in their care package and cost.</td>
</tr>
<tr>
<td>Improving market management</td>
<td>CCGs could renegotiate care home prices with providers, use collaborative procurement approaches and introduce framework agreements with suppliers.</td>
</tr>
<tr>
<td>Reviewing the CHC checklist and assessment tools</td>
<td>The Department is reviewing the CHC checklist and assessment tool as it recognises that the current process does not make best use of assessment staff. It expects the work will reduce the number of checklists and full assessments that are carried out.</td>
</tr>
</tbody>
</table>

Source: National Audit Office
Appendix One

Our investigative approach

Scope

1 This investigation sets out the facts relating to NHS continuing healthcare funding (CHC) and, in particular, access to CHC funding. It covers:

- who is eligible for CHC funding and what the assessment process is;
- how long the assessment and decision-making process takes;
- access to CHC funding;
- the cost of CHC to the NHS;
- variation in access to CHC funding; and
- what the Department of Health’s (the Department’s) and NHS England’s arrangements are for reviewing access to CHC funding.

2 We carried out our investigation between February and April 2017. Our investigation did not examine individual eligibility decisions or the delivery of CHC-funded services.

Methods

3 We interviewed relevant officials from the Department and NHS England. The work was designed to understand:

- the scope of NHS England’s strategic improvement programme and the measures taken to improve data quality;
- what support NHS England provides to help CCGs achieve the required efficiencies;
- the Department’s current review of the national framework; and
- the assurance processes for CCGs and NHS England.

We also interviewed other stakeholders including the Association of Directors of Adult Social Services, Beacon (a social enterprise that offers a CHC support service), the Continuing Healthcare Alliance (comprising a range of bodies), Marie Curie, the Parliamentary and Health Service Ombudsman and the Wales Audit Office to seek their views on access to CHC funding.
4 We reviewed the data analysis performed by NHS England and carried out our own analysis of the data provided by NHS England and NHS Digital. The data and analysis covered access to CHC and the costs, including numbers and outcomes of cases relating to previously unassessed periods of care. We also analysed data collected by the Continuing Healthcare Alliance, from 115 CCGs through Freedom of Information requests, on the average length of CHC assessments.

5 We reviewed relevant policy documents and announcements, operational guidance reports and meeting minutes relating to CHC from NHS England and the Department. We also reviewed reports and analysis from the Continuing Healthcare Alliance and the Wales Audit Office.

6 We reviewed information provided by individuals directly to the National Audit Office. See Appendix Two for further details.
Appendix Two

The main concerns raised by correspondents

1 Between February 2016 and July 2017, we received over 100 letters from members of the public raising concerns about NHS continuing healthcare (CHC). As the sample is self-selecting, with those who have experienced problems more likely to contact us, we cannot generalise the findings to the whole population that are assessed for CHC funding. However, the concerns raised helped us to understand the nature of potential problems and the impact that these can have on individuals. The table below summarises the most common concerns raised in this correspondence and Figure 17 on page 42 shows how the concerns raised relate to the eligibility process.
### Most common concerns

<table>
<thead>
<tr>
<th>The assessment process did not follow the national guidance and/or case law</th>
<th>Examples of the issues raised by correspondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessments did not follow or pay due regard to case law established by the Coughlan case.</td>
<td>Patient’s health needs were understated during the assessment resulting in ineligibility, despite evidence suggesting a primary health need.</td>
</tr>
<tr>
<td>Views and judgements of professionals were not requested, or were ignored or a lower score was awarded where professionals disagreed, despite the national framework stating that the higher score should be awarded in these cases.</td>
<td>Assessments did not take account of all the relevant information, or used inaccurate information. For example, verbal remarks were recorded incorrectly and written evidence was changed after the assessment.</td>
</tr>
<tr>
<td>Assessments did not reflect the views of the patient, family or patient representative as they were either not invited, not given adequate notice that an assessment was taking place or not fully involved in the assessment.</td>
<td>Assessments did not include professionals involved in the direct care of the individual or did not include the appropriate medical specialist.</td>
</tr>
<tr>
<td>The assessment team lacked the knowledge or experience to carry out a fair assessment, or took decisions for financial reasons.</td>
<td>The assessment team lacked the knowledge or experience to carry out a fair assessment, or took decisions for financial reasons.</td>
</tr>
</tbody>
</table>

| The quality and composition of the assessment team |
| Assessments did not include professionals involved in the direct care of the individual or did not include the appropriate medical specialist. |
| The assessment team lacked the knowledge or experience to carry out a fair assessment, or took decisions for financial reasons. |

| The process took too long and was subject to delays |
| Assessments exceeded the 28-day requirement or were delayed, for example, by a request for extra information after the assessment meeting. |
| There were long delays between the screening and full assessment. |
| The appeals process and assessment of previously unassessed periods of care took too long, sometimes years. |

| Poor communication with the patient, family and/or patient representative |
| CCGs did not: provide enough information about the process; inform the family that an assessment was taking place; and inform the family of the outcome. |
| CCGs withheld information about the assessment. For example, notes and evidence from the assessment meeting were not distributed. |
| CCGs either did not respond or were slow to respond to queries. |

| Complaints and appeals were mishandled |
| Appeals were ignored and there was a lack of communication about the progress of the complaint. |

| The assessment process is a burden on the patient and their representatives |
| Correspondents have paid for legal advice and help with their applications as well as for copies of medical and care records to support the application. |
| Families and representatives spend considerable amounts of time raising and responding to queries and producing the evidence for the assessment. |
Figure 17
Main concerns raised by correspondents

- Allegations of poor communication:
  - CCGs did not respond to communications; and
  - patients were not informed of the outcome of the assessment

- Assessments did not follow case law or the national framework:
  - patients, family and patient representatives were not invited to or informed about the assessment; and
  - relevant healthcare professionals were not invited to the assessment or their views were not reflected

- Allegations that health needs are downplayed or not recognised

- Assessments did not take account of all the relevant information/information was withheld or used inaccurate/falsified information
- Staff on the multidisciplinary team lacked knowledge or experience
- Additional information was requested following the meeting leading to delays

- Complaints about the appeals process:
  - complaints and appeals were ignored;
  - poor communication about the progress of the appeal; and
  - lengthy process

Note
1. The person may still be eligible for NHS-funded nursing care, a joint package of care or social care and should undergo the relevant assessments as set out in the national framework.

Source: National Audit Office
## Appendix Three

### CHC data

<table>
<thead>
<tr>
<th>The length of the assessment process</th>
<th>Data that would be helpful for evaluating whether CHC assessments are consistent with the national framework</th>
<th>Were the data available in 2015-16?</th>
<th>Did the data become available from April 2017?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>How long full assessments take on average.</td>
<td>No</td>
<td>Partly</td>
</tr>
<tr>
<td></td>
<td>Number of CHC assessments that take more than 28 days.</td>
<td>Yes</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>The reasons for delays.</td>
<td>No</td>
<td>Yes</td>
</tr>
</tbody>
</table>

| Appeals                              | Data on the first stage of the appeals process (asking the CCG to review the case) covering how many appeals are made, how long they take and how many are successful. | No                                | No                                       |
|                                      | Number of independent review panels, how long they take and the number which result in NHS England recommending a different eligibility decision. | Partly (data available on the number of appeals that result in NHS England recommending different eligibility decisions but not on the other areas). | No                                       |
|                                      | Number of complaints made to the Parliamentary and Health Service Ombudsman, the outcome of its reviews and how long they take. | Yes                               | N/A                                      |

| Access to funding                    | Number of people that are assessed as newly eligible for CHC through the standard and fast-track processes. | Yes                               | N/A                                      |
|                                      | Snapshot of number of people that are assessed as eligible to receive CHC funding at a point in time for the standard and fast-track processes. | Yes                               | N/A                                      |
|                                      | Number of referrals for CHC through the standard and fast-track processes.                       | Yes                               | N/A                                      |
|                                      | The proportion of people that are assessed as eligible for CHC through the standard and fast-track processes. | No (although a figure can be estimated from the available data). | Yes                                      |
### Access to funding continued

<table>
<thead>
<tr>
<th>Data that would be helpful for evaluating whether CHC assessments are consistent with the national framework</th>
<th>Were the data available in 2015-16?</th>
<th>Did the data become available from April 2017?</th>
</tr>
</thead>
<tbody>
<tr>
<td>The reasons why people are no longer eligible, such as they are reassessed and considered no longer eligible, or because they have died.</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>How long people receive CHC funding.</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Where assessments take place.</td>
<td>No</td>
<td>Partly (data available on the number of assessments that took place in acute hospital settings).</td>
</tr>
</tbody>
</table>

### Claims for previously unassessed periods of care

<table>
<thead>
<tr>
<th></th>
<th>Number of claims for previously unassessed periods of care and the number agreed eligible relating to the period from 1 April 2004 to 31 March 2012.</th>
<th>Yes</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number of claims for previously unassessed periods of care and the number agreed eligible relating to the period after 31 March 2012.</td>
<td>Partly</td>
<td>Partly</td>
</tr>
<tr>
<td></td>
<td>How long it takes CCGs to make decisions about claims for previously unassessed periods of care.</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

### The cost

<table>
<thead>
<tr>
<th></th>
<th>Budgeted spending on CHC.</th>
<th>Yes</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total outturn spending on CHC.</td>
<td>Yes</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>Average annualised cost of CHC per person.</td>
<td>No (although a figure can be estimated based on the available data).</td>
<td>No</td>
</tr>
</tbody>
</table>

### Notes

1. From 1 April 2017, NHS England expanded the data it collects on CHC to help address some data gaps and improve data quality.
2. Not all data that were available in 2015-16 were publicly available.

Source: National Audit Office
CORRECTION

Paragraph 7, third bullet, on page 10 and paragraph 3.8 on page 25 of the report were produced in error. The number of complaints received should have stated 600 and not 1,250.

Paragraph 7 currently reads:

7 It is not known how many people appeal against unsuccessful CHC funding decisions (paragraphs 1.11 and 3.8).

- If a patient is unhappy with the outcome of their assessment they can ask the CCG to review their case, but NHS England does not collect data on how many appeals are made to CCGs, how long they take or how many are successful.

- In 2015-16, 448 cases were reviewed by an independent review panel, because the patient was unhappy with the outcome of the CCG’s own review. In 27% of cases, NHS England recommended a different eligibility decision for part or all of the period reviewed.

- In 2015-16, the Parliamentary and Health Service Ombudsman received 1,250 complaints about CHC funding decisions. It investigated 181 of them and partly or fully upheld 36 cases.

It should read:

7 It is not known how many people appeal against unsuccessful CHC funding decisions (paragraphs 1.11 and 3.8).

- If a patient is unhappy with the outcome of their assessment they can ask the CCG to review their case, but NHS England does not collect data on how many appeals are made to CCGs, how long they take or how many are successful.

- In 2015-16, 448 cases were reviewed by an independent review panel, because the patient was unhappy with the outcome of the CCG’s own review. In 27% of cases, NHS England recommended a different eligibility decision for part or all of the period reviewed.

- In 2015-16, the Parliamentary and Health Service Ombudsman received 600 complaints about CHC funding decisions. It investigated 181 of them and partly or fully upheld 36 cases.
Paragraph 3.8 currently reads:

3.8 Organisations representing patients told us that many people that do not agree with the outcome of their assessment do not raise an appeal because they are too distressed to go through the complex appeals process. NHS England does not collect data on the number of decisions that are reviewed and overturned locally. However, in 2015-16, 448 cases were reviewed by an independent review panel, the second stage of the appeals process. In some 122 (27%) of cases, the panel recommended a different eligibility decision for either all or part of the period reviewed. In 2015-16, the Parliamentary and Health Service Ombudsman, the third stage of an appeal, received 1,250 complaints. It investigated 181 of them and partly or fully upheld 36 cases.

It should read:

3.8 Organisations representing patients told us that many people that do not agree with the outcome of their assessment do not raise an appeal because they are too distressed to go through the complex appeals process. NHS England does not collect data on the number of decisions that are reviewed and overturned locally. However, in 2015-16, 448 cases were reviewed by an independent review panel, the second stage of the appeals process. In some 122 (27%) of cases, the panel recommended a different eligibility decision for either all or part of the period reviewed. In 2015-16, the Parliamentary and Health Service Ombudsman, the third stage of an appeal, received 600 complaints. It investigated 181 of them and partly or fully upheld 36 cases.
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