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All or nothing? Access and variation in NHS continuing health care

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If you require information or support with NHS CHC, go to the Beacon website at: https://beaconchc.co.uk.

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NHS continuing health care (CHC) is a package of health and social care provided outside hospital, such as in an individual's own home or in a care home, which the NHS arranges and funds. If someone is assessed as eligible for CHC, the integrated care board (ICB) in that person's area must pay for all of their associated health and social care costs. It is for people aged 18 or over who have significant ongoing care needs that arise from a 'primary health need'. People who are ineligible for CHC can be faced with a cliff-edge of potentially catastrophic costs for the social care they need. Or, if they fall under the financial threshold during a social care means test, their local authority may be required to pay part or all of the costs of their care.

CHC is a vital source of support for people with some of the most complex health and care needs. Its existence goes to the heart of both the moral and practical debates about how we do (and should) fund and provide care for people with complex needs outside hospital. But it has become a microcosm of the dysfunctions that a cash-strapped, paltry social care system and a struggling NHS have wrought. At the heart of the issue are individuals and their families who are faced with a complex and challenging process at the most difficult time. Our conversations with people who had been through the CHC process for their families demonstrated that not only is the assessment process itself challenging, but the toll it takes is also long-lasting, part of an ongoing struggle to access good-quality, timely care for their loved ones.

Looking at the CHC funding process provides a window into how our health and care systems work together – or perhaps more accurately, how they do not. CHC sits within a complex ecosystem of different accountability, funding and eligibility processes, and is one part of a bigger picture around providing care for people who need it. It offers a prism through which some of the fundamental issues at the interface of health and social care can be understood.

This research set out to shine a light on what is happening with CHC in England, in particular the variation in access and eligibility that exists.

Since we began the work, there have been several developments in the external environment that have made the issues we have identified and our recommendations even more critical. These include the announcement that the functions of NHS England are to be brought back into the Department of Health and Social Care.[1] With ICBs also expected to make cuts to their running costs, pressures on CHC will be exacerbated even further.

Key findings

Against the backdrop outlined above, our research found that:

- The number of people eligible for CHC has fallen over time and varies significantly across England.

- Population need explains some of the variation. We found that sub-ICB locations – organisational units below ICBs and formerly clinical commissioning groups – with higher levels of deprivation, and larger populations aged 75 and over, are more likely to have higher rates of CHC. However, our analysis also found that local area characteristics cannot fully explain the variation in eligibility.

- Spending on CHC has increased over time but is not distributed equally. Spending per eligible recipient is lower in the north of England, even after adjusting for geographical differences.

- CHC practice and variation are complex and multi-faceted – many factors at individual, organisational and system levels drive them. These include:
  - how different local areas approach CHC
  - the knowledge and awareness of CHC among the people involved in the process
  - where referrals come from
  - the quality of local relationships, with CHC acting as a temperature check on broader integration efforts.

1 Department of Health and Social Care (2025) 'World's largest quango scrapped under reforms to put patients first', press release, 13 March. www.gov.uk/government/news/worlds-largest-quango-scrapped-under-reforms-to-put-patients-first. Accessed 30 July 2025.

- There are concerns that financial pressures are playing a key role in the operation of CHC, with all parts of the system facing significant pressure to keep costs down.

The need for reform

Many of the challenges we have identified stem from the way that health and social care are separate systems, with different funding streams and accountability structures. As such, this research underscores the need for action on comprehensive long-term care reform. This should be designed around a person's needs and be less likely to result in unfair financial 'cliff edges' whereby individuals suddenly find themselves facing significant care costs. The current situation means the stakes are high – an 'all or nothing' approach that is problematic and does not reflect the nature of need. With both the NHS and social care under pressure to keep costs down and allocate resources equitably, people requiring care are caught in the middle.

The Casey Commission – an independent commission into adult social care – offers a vital opportunity to start to build a strong social care system that can work alongside the NHS as an equal partner. In any reforms that follow, it is essential that supporting people with needs spanning health and social care is a central consideration. There is potential to learn from other countries where the demarcation between health and care systems is effectively bridged through clarity of entitlement, consistency of the care offer and – crucially – the existence of a long-term care system that is supported through stable funding.

Notwithstanding the need for wider reform, urgent action is required to improve consistency and fairness in how CHC currently operates. While this would not address the fundamental issues, it would ensure that the current system is operating most effectively for the people who need it now. Importantly, doing nothing is not an option. If the government is to make its ambition to shift care from hospital into the community a reality, addressing the problems in CHC will be an important step.[2]

2 Department of Health and Social Care (2025) 'Fit for the future: 10 Year Health Plan for England – executive summary'. www.gov.uk/government/publications/10-year-health-plan-for-england-fit-for-the-future/fit-for-the-future-10-year-health-plan-for-england-executive-summary#from-hospital-to-community-the-neighbourhood-health-service-designed-around-you. Accessed 30 July 2025

Our recommendations

Our recommendations to improve current practice include:

- improving consistency in CHC through:
  - spreading good practice
  - sharing learning
  - training
  - ensuring that assessments are conducted in line with the requirements of the National Framework[3] for NHS Continuing Healthcare and NHS-funded Nursing Care

- understanding who is and who is not accessing CHC by proactively capturing and analysing information about where referrals are coming from, CHC assessments and eligibility by demographics, and using the information provided in the NHS CHC Patient Level Data Set[4] to monitor and address potential inequalities in access

- improving commissioning practices through:
  - collaborative working that enables appropriate and personalised care for people with complex needs
  - proactive working between integrated care system partners to shape the local provider market
  - establishing clear and transparent processes and policies for how care is commissioned for people eligible for CHC

- supporting integration through:
  - ensuring clear and effective dispute resolution policies
  - evaluating alternative processes to managing and funding CHC
  - identifying best practice at a local level

3 Department of Health and Social Care (2022) *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care*. GOV.UK. https://assets.publishing.service.gov.uk/media/64b0f7cdc033c100108062f9/National-Framework-for-NHS-Continuing-Healthcare-and-NHS-funded-Nursing-Care_July-2022-revised_corrected-July-2023.pdf.

4 NHS Digital (no date) 'NHS Continuing Health Care (CHC) Patient Level Data Set'. https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/continuing-health-care-data-set. Accessed 1 August 2025.

- ensuring clear governance and accountability for CHC within the context of the Model ICB Blueprint[5] and changes to the role of NHS England
- the Care Quality Commission considering CHC as part of its assessment
- the National Audit Office investigating how CHC is funded and delivered and whether improvements can be made.

5 NHS England (2025) *Model Integrated Care Board – Blueprint v1.0*. www.digitalhealth.net/wp-content/uploads/2025/05/Model-Integrated-Care-Board-%E2%80%93-Blueprint-v1.0.pdf.

1 Introduction

NHS continuing health care (CHC) in England is a package of health and social care provided outside hospital, such as in an individual's own home or a care home, which the NHS arranges and funds.[6] It is for individuals aged 18 or over who have significant ongoing care needs that arise from a 'primary health need'.

Issues relating to CHC are long-standing. In 2013, an All Party Parliamentary Group (APPG) on Parkinson's investigation concluded that the system was 'not fit for purpose', pointing to a litany of failures for individuals, their families and the wider system.[7] This was reflected in a National Audit Office (NAO) report a few years later, which highlighted several concerns around the assessment process for individuals and their families, as well as a lack of assurance to ensure consistency in decision making.[8] Most recently, research from Age UK has shown that these issues – including a lack of awareness about CHC and difficulties with the process – persist for older people in particular.[9] These issues were reflected in the conversations we had with people who had supported relatives trying to access CHC funding. Taken together, this demonstrates that CHC has a significant impact on people at what is an already challenging and difficult time, and the consequences of being assessed as ineligible can be huge.

6 Wales and Northern Ireland adopt a similar approach to England. In Scotland, following an independent review of NHS Continuing Health Care in 2014, the scheme was replaced by Hospital Based Complex Clinical Care in 2015. Further information can be found at: Dodsworth and Oung (2023) Other types of support: how do the other countries compare? www.nuffieldtrust.org.uk/news-item/other-types-of-support-how-do-the-countries-compare-1. Accessed 14 August 2025.

7 All Party Parliamentary Group on Parkinson's (2013) *Failing to Care: NHS continuing care in England*. https://chcfunding.wordpress.com/wp-content/uploads/2014/03/failing-to-care_appg-ful-lreport-2013.pdf.

8 Comptroller and Auditor General (2017) *Investigation into NHS Continuing Healthcare Funding*. National Audit Office. www.nao.org.uk/reports/nhs-continuing-healthcare-investigation/?nab=1. Accessed 1 August 2025.

9 Gentry T (2024) *Continuing to Care? Older people let down by NHS continuing healthcare*. Age UK. www.ageuk.org.uk/siteassets/documents/reports-and-publications/consultation-responses-and-submissions/health--wellbeing/continuing-to-care---nhs-continuing-healthcare-report.pdf.

Over time, while the issues have remained, the context has evolved. CHC initially emerged in the 1990s as a result of the closure of long-stay hospital beds, leading to an increasing number of people requiring care outside hospital. Most recently, one of the government's 'three shifts' – moving care from hospital into the community – reflects this long-standing ambition.[10]

This research set out to shine a light on what is happening with CHC and what it tells us about the key issues facing health and social care. Since we began the work, there have been several developments in the external environment, which have made the issues we have identified and our recommendations even more critical. This includes the announcement that the functions of NHS England are to be brought back into the Department of Health and Social Care.[11] At the same time, ICBs have been asked to reduce their running costs by 50% by October 2025, with variation in CHC spend identified as a key area that requires addressing, although it is unclear whether this relates only to unwarranted variation.[12] In addition, the 'Model ICB Blueprint' – which sets out a programme to reshape the role and functions of ICBs in light of proposed funding cuts – raises questions for CHC. The Blueprint identifies it as an area where ICBs should 'test and explore options to streamline and transfer some activities out of ICBs'.[13] So there is significant uncertainty in the wider context, and CHC remains a key issue.

10 Change NHS (2025) 'The three shifts: an NHS fit for the future'. https://change.nhs.uk/en-GB/projects/three-shifts. Accessed 1 August 2025.

11 Department of Health and Social Care (2025) 'World's largest quango scrapped under reforms to put patients first', press release, 13 March. www.gov.uk/government/news/worlds-largest-quango-scrapped-under-reforms-to-put-patients-first. Accessed 1 August 2025.

12 West D, Anderson H and Kituno N (2025) 'ICBs ordered to cut costs by 50%', *HSJ*, 12 March. www.hsj.co.uk/policy-and-regulation/icbs-ordered-to-cut-costs-by-50/7038846.article. Accessed 1 August 2025.

13 NHS England (2025) *Model Integrated Care Board – Blueprint v1.0*. www.digitalhealth.net/wp-content/uploads/2025/05/Model-Integrated-Care-Board-%E2%80%93-Blueprint-v1.0.pdf.

Aims of this research

In 2024, the Nuffield Trust undertook initial exploratory research on CHC.[14] This involved analysing publicly available NHS data on CHC assessments and eligibility, speaking to stakeholders and reviewing previous reports and investigations. This revealed significant variation across England regarding the numbers of people assessed and found eligible for CHC, raising concerns about access and consistency.

Building on that initial analysis, this mixed-methods project aimed to explore variation and inequalities in relation to CHC in more detail. In particular, the research aimed to:

- better understand factors affecting CHC variation
- understand what – if any – action local systems are taking to address this variation
- where possible, explore the relationship between CHC and patient/local characteristics (including deprivation, patient need and demographic characteristics such as gender, age and ethnicity)
- identify implications and make recommendations for the health and social care system.

14 Hutchings R, Davies M and Curry N (2024) 'Falling through the gaps: a closer look at NHS continuing healthcare'. www.nuffieldtrust.org.uk/resource/falling-through-the-gaps-a-closer-look-at-nhs-continuing-healthcare. Accessed 1 August 2025.

2 Methods

For this research on NHS CHC, we used a mixed-methods approach. A detailed methodology is presented in the Appendix. In summary, we carried out the following:

- We spoke to 44 stakeholders from across the health and care system.
- We reviewed the 2022/23 annual reports of all 42 integrated care boards (ICBs) to identify information about local experiences of CHC.
- We reviewed all ICB websites to identify publicly available policies on commissioning care for people eligible for CHC. In total, as of September 2024, we identified 11 documents, which we then analysed.
- We spoke to three people with lived experience of the CHC process. We have not reported on their individual experiences in this report but we have used our conversations with them to inform our understanding of the context, our research approach and our recommendations.
- We used NHS England's published data on CHC, specifically drawing on the number of adults eligible for CHC and the number of adults newly assessed as eligible. At the time of our analysis, these data were available from the first quarter of the financial year in 2017/18 (April–June 2017) to the third quarter of the financial year in 2024/25 (October–December 2024).
- We performed a linear regression analysis to test the relationship between CHC eligibility and proxies of need, specifically age and deprivation.
- We sent Freedom of Information requests to each of the 42 ICBs to better understand the data they collect locally and, where possible, to receive data on assessments and eligibility by patient characteristics, including age, sex, ethnicity and diagnosis type. The quality and consistency of these data were variable. We therefore used publicly available local area

information – such as data on deprivation, population demographics, and level of urbanisation – where possible, to add to this analysis.

- We sent a Freedom of Information request to NHS England on spending on CHC across the NHS as a whole and by individual ICBs.

- We conducted seven semi-structured interviews with 10 individuals from four ICB CHC teams and eight interviews with 10 individuals from seven local authorities.

- We held three focus groups with care providers involving a total of 23 participants. These were supplemented with one interview with a care provider and two questionnaire responses (we sent individuals who expressed an interest in taking part in a focus group but who were unable to join a discussion a brief online questionnaire, which invited them to share their experiences in relation to the same topics covered in the focus groups).

- We held an online workshop attended by 18 stakeholders to share our emerging findings and help us to develop our recommendations.

We used inductive thematic analysis to identify themes from the qualitative data.

This research focused on CHC for adults in England and included both standard and fast-track CHC. While we have identified several important themes, CHC is complex and we have not been able to cover every issue exhaustively.

Table 1: Table of definitions

Term	Definition
Number of people eligible for CHC	Total number of people recorded as eligible for CHC in NHS Continuing Healthcare statistics (this does not tell us about the numbers receiving care or when they began receiving care, nor about unmet need).
Number of completed referrals (including discounted referrals)	The number of completed referrals for CHC. A referral is the earliest notification to the ICB or organisation acting on behalf of the ICB that full consideration for NHS CHC is required (for example, following a positive checklist assessment, use of the 'fast-track pathway tool' or other notification that full consideration is required).
Assessment conversion rate	The proportion of people assessed as eligible for CHC following a CHC assessment.
Rate per 50,000	The number of adults eligible for CHC per 50,000 population (not age-standardised). Rates are calculated using GP registrant population data for the middle month in the quarter.
Number of people newly assessed in quarter found eligible for CHC	Number of people newly assessed as eligible for CHC in the relevant time period.
Sub-ICB location	An area formerly known as a clinical commissioning group. Sub-ICB locations are organisational units below ICBs. NHS England now submits data for CHC by sub-ICB location. We explore patterns in both ICBs and sub-ICB locations where relevant.

3 What is NHS continuing health care (CHC)?

NHS continuing health care (CHC) is a package of health and social care provided outside hospital, such as in an individual's own home or a care home, which the NHS arranges and funds. CHC is for individuals aged 18 and over who are deemed to have a 'primary health need' arising from illness, accident or disability and who require care to support that need. It is organised into two streams – standard and fast-track – the latter being for people whose condition is rapidly deteriorating, many of whom are approaching the end of life.[15]

Primary health need

The concept of 'primary health need' developed from case law.[16] According to the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care,[17] an individual has a primary health need if 'having taken account of all their needs… it can be said that the main aspects or majority part of the care they require is focused on addressing and/or preventing health needs'. Whether someone has a primary health need does not depend on the presence of a particular diagnosis, but on the totality of the level and type of their day-to-day care needs that may arise from illness or disability. What this looks like in practice is often not clear cut.

15 Children and young people aged 0–17 with ongoing needs are covered by the process for assessing children and young people's continuing care; see Department of Health and Social Care (2016) 'Children and young people's continuing care national framework'. www.gov.uk/government/publications/children-and-young-peoples-continuing-care-national-framework. Accessed 1 August 2025

16 Beacon (no date) 'Coughlan & case law'. https://beaconchc.co.uk/faqs/coughlan-case-law. Accessed 1 August 2025.

17 Department of Health and Social Care (2022) *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care*. GOV.UK. https://assets.publishing.service.gov.uk/media/64b0f7cdc033c100108062f9/National-Framework-for-NHS-Continuing-Healthcare-and-NHS-funded-Nursing-Care_July-2022-revised_corrected-July-2023.pdf.

If someone is assessed as eligible for CHC, the integrated care board (ICB) in their area is legally responsible for covering all of their assessed health and social care costs. If they are not eligible for CHC, they may qualify for NHS-funded nursing care, which is when the NHS pays for the nursing care component of fees if the person lives in a nursing home.[18] If they are found ineligible for CHC and do not qualify for NHS-funded nursing care, they would need to approach their local authority for a social care needs assessment and a financial means test, which will determine whether they are eligible for social care funding. Eligibility for social care funding in England is complex and there are several different streams depending on the nature of the person's needs (see Table 2 for an overview). If an individual both meets the social care needs threshold and falls below the financial means threshold, the local authority may pay some or all of the costs of their care. However, if they do not, they can be faced with potentially significant costs for the care they need. Therefore, the implications for someone not being found eligible for CHC are significant for both individuals and local authorities.

18 While we recognise there are also issues with NHS-funded nursing care, the focus of this report is on CHC.

Table 2: Overview of publicly funded streams for social care provided outside hospital for adults in England

NHS CHC	NHS-funded nursing care	Mental Health Act 1983, section 117 aftercare	Local authority funded social care
Who is eligible?			
Those assessed as having health and care needs arising from a 'primary health need', who then have either standard or fast-track CHC.	Those who are living in a nursing home and are assessed as requiring care from a registered nurse, but who are not eligible for CHC.	Those who have been detained in hospital under certain sections of the Mental Health Act* and are discharged onto a community treatment order or are on a conditional discharge.	Those with care and support needs meeting 3 criteria set out in the Care Act 2014 and who have less than £23,250 (upper capital limit) or £14,250 (lower capital limit) – in income, assets or savings.
What is covered?			
All assessed health and care costs, whether provided in the person's own home or another setting, including the cost of residential accommodation where that is required. Neither individuals nor third parties can make top-up payments. People eligible for CHC are entitled to a Personal Health Budget.	The nursing care component of nursing home fees – services that a registered nurse provides, such as monitoring or treating medical conditions (rather than support with personal care). It is paid directly to the nursing home, at a standard rate of £254.06 a week or a higher rate of £349.50 a week – both as of 1 April 2025.	Aftercare services, which meet a need relating to a mental health diagnosis and help prevent deterioration or hospital readmission (can include health care, social care or supported accommodation). Note: a person may also be eligible for CHC if they have additional needs that section 117 aftercare does not cover.	The local authority must provide the individual with a person-led care and support plan. This includes a personal budget – an estimate of the total care costs that the local authority will fund. A third party can top up care fees if care home costs are more than what the local authority is willing to pay.
Who is responsible for assessing need and commissioning care?			
ICB	ICB	ICB and local authority	Local authority

Note: This overview does not include self-funded social care. *The sections are 3, 37, 45A and 47 or 48.[19]

19 Mind (no date) 'Section 117 aftercare'. www.mind.org.uk/information-support/legal-rights/leaving-hospital/section-117-aftercare. Accessed 1 August 2025.

How is CHC eligibility assessed?

CHC began initially at a local level, where areas developed their own approaches and criteria for assessing and funding individuals. Since then, there have been numerous attempts to clarify and standardise the approach to CHC through legal cases, legislation and guidance, culminating in the first National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care, introduced in 2007 (updated most recently in 2022).[20] This sets out the process and principles that must be followed to determine whether an individual is eligible for CHC, based on a combination of legislation and regulations. As noted earlier in this chapter, to be eligible for CHC, a person must have been assessed as having a 'primary health need'. This is not based on diagnosis, but on an assessment of all of their relevant health and care needs. The Decision Support Tool aims to support with assessment and decision making.[21]

The assessment process is broken down into several stages (see Figure 1 for a summary). First, a health and care professional – such as a general practitioner, nurse or social worker – completes a checklist as a screening step. Then, a multidisciplinary team conducts a more in-depth assessment of the person's needs, with a decision on eligibility due within 28 days.[22] The eligibility threshold for progressing from the checklist is set intentionally low, to reduce the number of individuals who miss out on an appropriate assessment.[23] But this also means that many people who have a full assessment are not found to be eligible for CHC: in quarter 3 of 2024/25

20 Department of Health and Social Care (2022) *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care*. GOV.UK. https://assets.publishing.service.gov.uk/media/64b0f7cdc033c100108062f9/National-Framework-for-NHS-Continuing-Healthcare-and-NHS-funded-Nursing-Care_July-2022-revised_corrected-July-2023.pdf.

21 Department of Health and Social Care (2022) 'NHS continuing healthcare decision support tool guidance'. www.gov.uk/government/publications/nhs-continuing-healthcare-decision-support-tool/nhs-continuing-healthcare-decision-support-tool-guidance. Accessed 1 August 2025.

22 Department of Health and Social Care (2022) *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care*. GOV.UK. https://assets.publishing.service.gov.uk/media/64b0f7cdc033c100108062f9/National-Framework-for-NHS-Continuing-Healthcare-and-NHS-funded-Nursing-Care_July-2022-revised_corrected-July-2023.pdf.

23 Department of Health and Social Care (2022) 'NHS continuing healthcare checklist guidance'. www.gov.uk/government/publications/nhs-continuing-healthcare-checklist/nhs-continuing-healthcare-checklist-guidance. Accessed 1 August 2025.

13,288 people had a full assessment, but only 2,474[24] were found to be eligible for standard CHC.

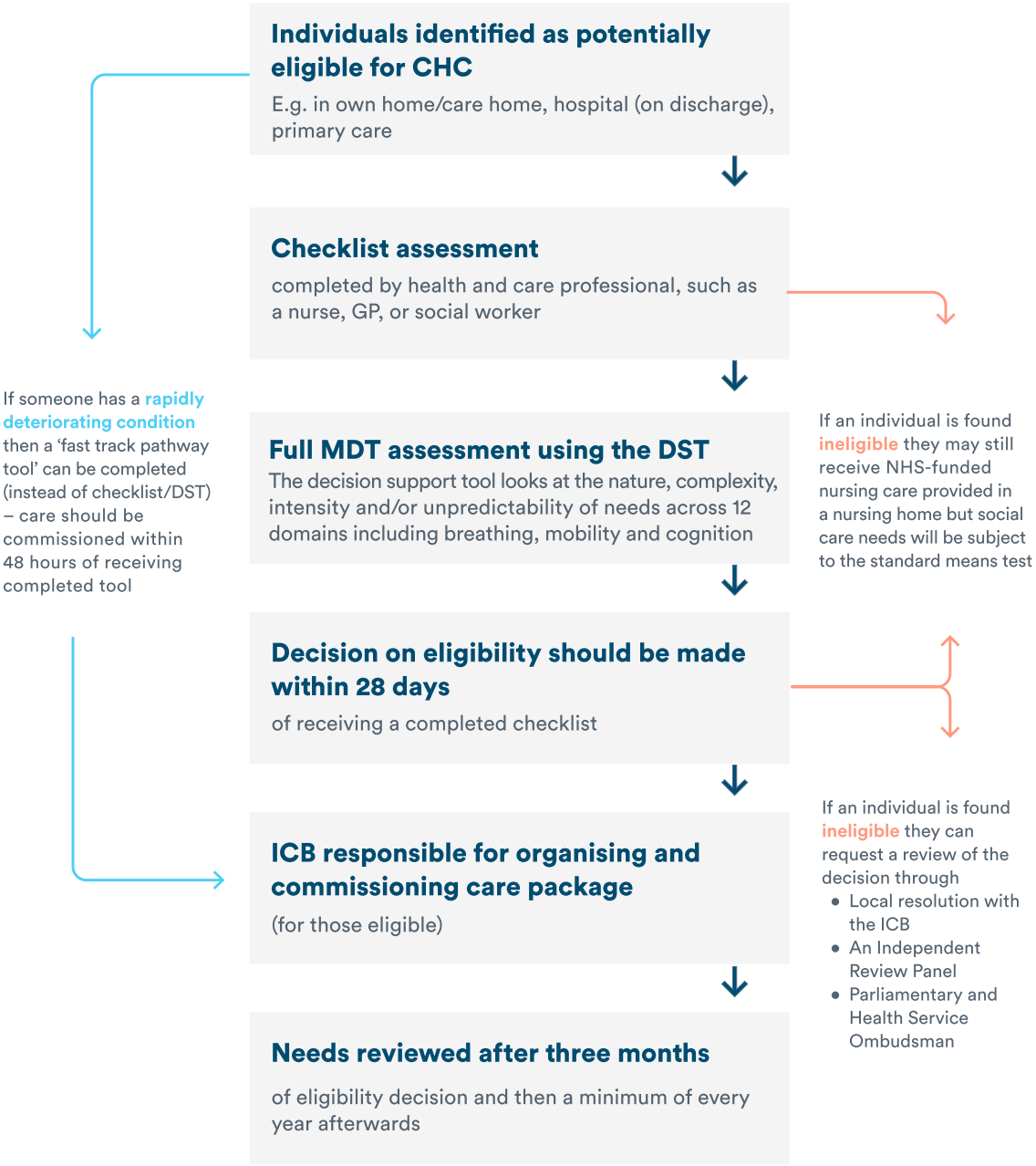
For those who are eligible for CHC, the integrated care board (ICB) puts the care in place, reviewing the person's eligibility after three months, then annually.

For those whose condition is deteriorating rapidly (for example, they may be entering the terminal phase of life), then a nurse or doctor involved in diagnosing, treating or caring for the person should complete a 'fast-track pathway tool' after the assessment. In this case, there is no requirement to also complete a Decision Support Tool.[25] This is a one-step process and care should then be in place within 48 hours.

24 This is not presented as a proportion, because the number eligible in this quarter may not necessarily have had an assessment in that same quarter. This is because a eligibility decision can be made up to 28 days after an assessment, so there will be a reporting time difference.

25 Department of Health and Social Care (2022) 'Fast-track pathway tool for NHS continuing healthcare guidance'. www.gov.uk/government/publications/nhs-continuing-healthcare-fast-track-pathway-tool/fast-track-pathway-tool-for-nhs-continuing-healthcare-guidance. Accessed 1 August 2025.

Figure 1: Overview of the referral, assessment and appeals process for NHS CHC



Who is responsible for CHC?

ICBs are legally accountable for CHC and took over the responsibility from clinical commissioning groups in 2022. Their role includes:

- ensuring compliance with secondary legislation (the 'Standing Rules')[26]
- having regard to the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care
- making decisions on CHC eligibility
- commissioning care for eligible individuals
- adhering to quality standards.

NHS England holds ICBs to account and collects data to monitor their performance. These include:

- the numbers of referrals, assessments and eligible individuals for standard and fast-track CHC
- the number of assessments that take place in a community setting
- the number of eligibility decisions made within 28 days.

Local authorities also have a key role to play in CHC. Under the Care Act 2014, they are obliged to identify people with care needs and refer them for assessments – including CHC – as appropriate. And, although they do not make decisions on CHC eligibility, they should work closely with ICBs as part of the assessment and commissioning process. As noted earlier, people who are not eligible for CHC may be eligible to receive local authority-funded social care.

26 The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012. www.legislation.gov.uk/uksi/2012/2996/part/6. Accessed 13 August 2025.

CHC developed from a recognition that many people with care needs can be best supported outside a hospital environment, and its implementation interacts with other policies. For example, during the Covid-19 pandemic, the Discharge to Assess policy (and associated funding) encouraged acute hospitals to discharge patients so that their needs could be assessed in a community setting. This accelerated an increase in the number of CHC assessments being done outside hospital, a programme of work that had begun before the pandemic.[27] Between October and December 2024 almost all Decision Support Tool assessments took place outside an acute hospital.

The impact of CHC on individuals, families and carers

We recognise that behind CHC legislation, regulation, processes and data, are people often in extremely difficult circumstances. Several organisations and journalists have reported on the impact of the CHC process.[28,29] Not only do people potentially face catastrophic costs if they are not eligible for funding, but also, to reach an eligibility decision, many have had to go through what feels like a gruelling process. And even if someone is found eligible, there is a risk that they can be found ineligible upon review and have their funding withdrawn, which can have a big impact further down the line.

27 Department of Health and Social Care (2024) 'Hospital discharge and community support guidance'. www.gov.uk/government/publications/hospital-discharge-and-community-support-guidance/hospital-discharge-and-community-support-guidance. Accessed 1 August 2025.

28 Parkinson's UK in association with the Continuing Healthcare Alliance (2017) *Continuing to Care? Is NHS continuing healthcare supporting the people who need it in England?*. www.parkinsons.org.uk/sites/default/files/2017-08/cs2332_continuing_to_care_report.pdf.

29 Eley A and Holt A (2024) 'Families of disabled people tell BBC of battle for NHS care support', BBC News, 14 February. www.bbc.co.uk/news/health-68238040. Accessed 1 August 2025.

Age UK's report on CHC highlighted negative experiences across the whole CHC pathway, from knowing about CHC, to distressing assessments with professionals who lack understanding about the person's condition – all while navigating the complex health and care system.[30]

The National Audit Office's investigation into CHC highlighted how delays in decisions lead to additional stress for families.[31] And the Parliamentary and Health Service Ombudsman published a report highlighting the importance of getting assessments and care packages right the first time, so that families do not face financial uncertainty, or unnecessary stress and anxiety, or provide large amounts of unpaid care.[32]

30 Age UK (2024) *Continuing to Care? Older people let down by NHS continuing healthcare.* Age UK. www.ageuk.org.uk/siteassets/documents/reports-and-publications/consultation-responses-and-submissions/health--wellbeing/continuing-to-care---nhs-continuing-healthcare-report.pdf.

31 Comptroller and Auditor General (2017) *Investigation into NHS Continuing Healthcare Funding*. National Audit Office. www.nao.org.uk/reports/nhs-continuing-healthcare-investigation/?nab=1. Accessed 1 August 2025.

32 Parliamentary and Health Service Ombudsman (2020) *Continuing Healthcare: Getting it right first time.* Parliamentary and Health Service Ombudsman. www.ombudsman.org.uk/publications/continuing-healthcare-getting-it-right-first-time. Accessed 1 August 2025.

4 Shifting picture: trends and variation in CHC assessments and eligibility

Key takeaways

- The number of people eligible for CHC fell from 57,216 at the end of June 2017 to 52,008 at the end of December 2024 – a fall of 9.1%.[33]

- In all years, with the exception of 2020/21, we found a statistically significant fall in the average number of people eligible for CHC in the last two quarters of the financial year compared to the first two. The exact reason for this pattern is not clear, but the financial pressures the ICBs are under are widely acknowledged and these may be playing a part.

- Although the number of people eligible for CHC fell in the period studied, the total number of referrals completed[34] rose. Fast-track cases primarily drove the rise in CHC referrals – these increased by 30.9%, from 21,769 to 28,498 within the same period.

- National data show that since the end of July 2017/18, all individuals assessed for fast-track CHC have been found eligible. However, eligibility for standard CHC has fallen, with less than a fifth (18.6%) of assessed individuals found eligible in October–December 2024 compared to just under a third (31.2%) in April–June 2017.

33 Quarterly snapshot data: from Q1 2017/18 (last day of June 2017) to Q3 2024/25 (last day of December 2024).

34 The number of referrals completed including discounted referrals (both standard and fast-track CHC).

- Variation persists. On 31 December 2024, the variation in the numbers of people assessed as eligible ranged from 20 to 95 per 50,000 adults between ICBs, reflecting an almost five-fold difference between the ICBs with the highest and lowest rates of CHC.[35]

How many people are eligible for CHC?

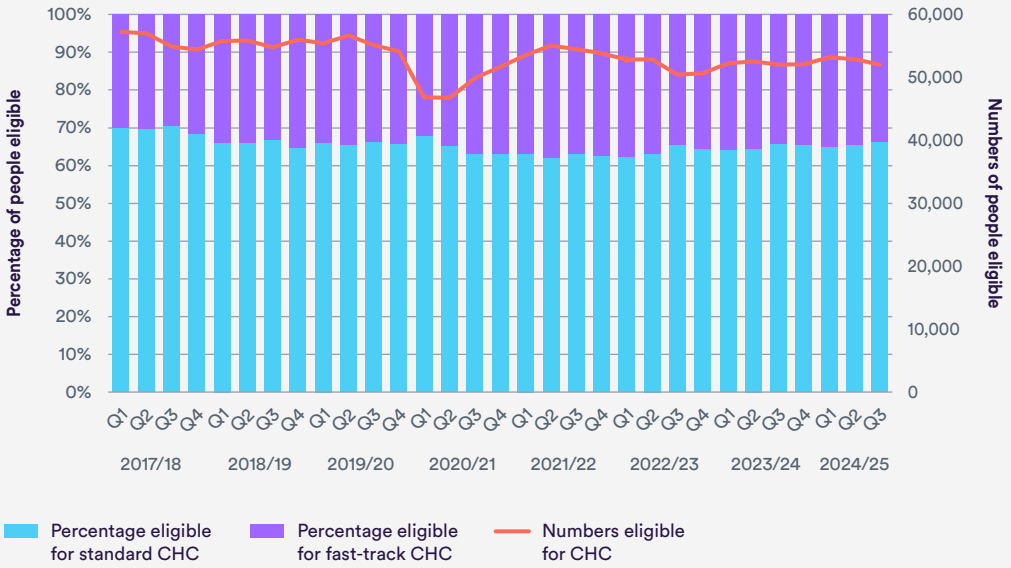
As people are continually being assessed for CHC while others no longer require it or become ineligible, the total **number of people eligible for CHC** at any one time changes constantly. At the end of December 2024, the total number of people eligible for CHC funding (for both standard and fast-track CHC) was 52,008, falling 9.1% from 57,216 at the end of June 2017 (see Figure 2).[36] Fast-track recipients make up around a third of those eligible for CHC.

In all years, with the exception of 2020/21 during the Covid-19 pandemic, we found a statistically significant fall in the average number of people eligible for CHC in the last two quarters of the financial year compared to the first two. The exact reason for this pattern is unclear. However, it is widely recognised that ICBs face significant financial pressures, which may result in unfair processes when determining CHC eligibility towards the end of the financial year. This is explored in greater depth in the following chapters.

35 Quarterly snapshot data: from Q3 2024/25 (last day of December 2024). Rates were calculated using GP registrant data in November 2024.

36 Quarterly snapshot data: Q1 2017/18 (last day of June 2017) to Q3 2024/25 (last day of December 2024).

Figure 2: Percentage of people eligible for standard versus fast-track CHC, and total numbers eligible for CHC



Source: Nuffield Trust analysis of NHS England data

Although fewer people are now being found eligible for CHC, the total **number of completed referrals**[37] rose by 13.5% from 40,380 in April–June 2017 to 45,848 in October–December 2024,[38] as published in the national data (see Figure 3). Fast-track cases primarily drove the rise in CHC referrals, which increased by 30.9%, from 21,769 to 28,498, within the same period. In contrast, standard CHC referrals declined by 6.8%, from 18,611 to 17,350, potentially indicating that patients are being referred at a later stage in their condition.

However, as some referrals are discounted following the completion of a checklist (see Chapter 3), not everyone initially referred to CHC will receive a full assessment to determine whether they are eligible. Referrals can be discounted for various reasons, including:

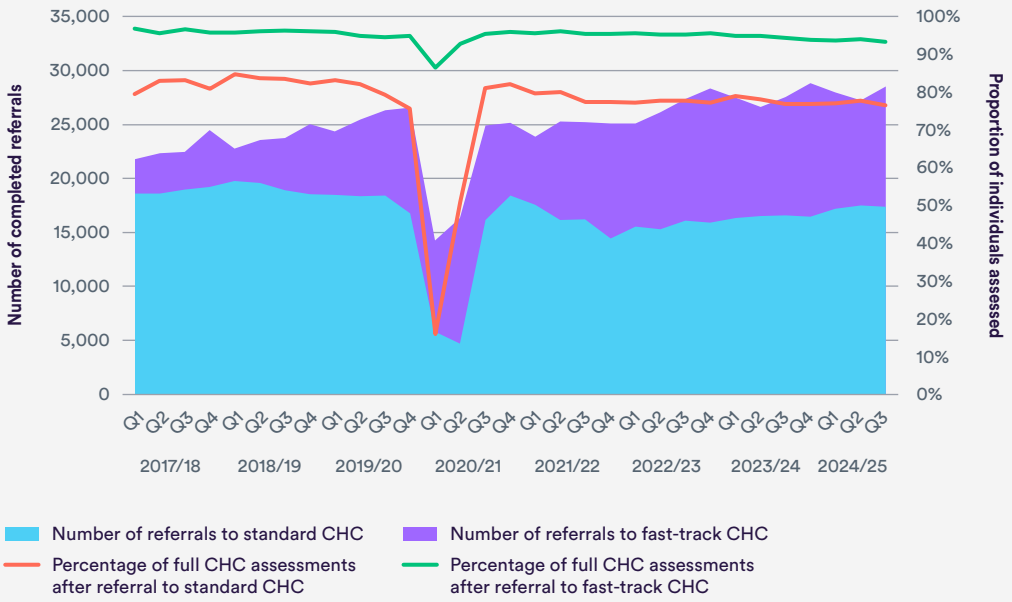
- decisions that the ICB or the individual themselves make
- the need for further acute treatments
- the individual has since passed away.

37 The number of referrals completed including discounted referrals (for both standard and fast-track CHC).

38 In-quarter data – the cumulative total from the first day of the quarter to the last day of the quarter.

Here, we calculated the proportion of referrals that led to an assessment. In October–December 2024, 93.4% of individuals referred for fast-track CHC were assessed, compared to 76.6% for standard CHC (see Figure 3).[39] Over the time period under study, the proportion of completed assessments fell slightly (see Figure 3).

Figure 3: Change in the number of referrals to CHC and the proportion of individuals assessed after referral



Source: Nuffield Trust analysis of NHS England data

The proportions of those found eligible (sometimes referred to as the **assessment conversion rate**) for standard CHC and for fast-track CHC differ and have changed over time. National data show that since the end of July 2017/18, all individuals assessed for fast-track care have been found eligible.[40] However, eligibility for standard CHC has fallen, with less than a fifth (18.6%)

39 In-quarter data represent the cumulative total from the first day of the quarter to the last day of the quarter.

40 This is likely due to the fact that a completed 'fast-track pathway tool', which clearly evidences that the person meets the criteria for fast-track funding, is sufficient to establish eligibility. For information on the tool, see Department of Health and Social Care (2022) *Fast Track Pathway Tool for NHS Continuing Healthcare*. GOV.UK. https://assets.publishing.service.gov.uk/media/62fd04148fa8f504bd845834/Fast-Track-Pathway-Tool-for-NHS-Continuing-Healthcare-guidance.pdf.

of assessed individuals found eligible in October–December 2024 compared to just under a third (31.2%) in April–June 2017.[41]

How does CHC eligibility vary across England?

Variation in rates of adults eligible for CHC

Data on the number of adults eligible for CHC is given per 50,000 population – **rate per 50,000**. As at 31 December 2024, the rate of adults eligible for CHC varied between ICBs, – from 20 to 95 per 50,000 adults, representing an almost five-fold difference between the ICBs with the highest and lowest rates of CHC – but this was different depending on whether it was standard or fast-track CHC they were eligible for.[42] Eligibility for fast-track CHC ranged from 6 to 47 per 50,000 adults between ICBs, demonstrating a stark difference where the rate among ICBs with the highest rate was almost eight times greater than that for ICBs with the lowest rate. Similarly, standard CHC eligibility varied between 10 and 67 per 50,000 adults, reflecting a six-fold difference between the ICBs with the highest and lowest rates of CHC.

Looking at the geographical distribution of CHC eligibility rates shows a notable pattern across England. As at 31 December 2024, standard CHC eligibility rates were higher in the north of England and the North West, compared to the south including areas such as Cornwall and London (see Figure 4). A similar pattern, albeit less pronounced, was also evident in the eligibility rates for fast-track CHC, with the North West again having comparatively higher rates of eligibility compared to the rest of England (see Figure 5).

41 The proportion of eligible cases of total cases assessed using in-quarter data. In-quarter data represent the cumulative total from the first day of the quarter to the last day of the quarter.

42 Snapshot data from Q3 2024/25. Rates were calculated using GP registrant data in November 2024.

Figure 4: CHC eligibility rates per 50,000 adults for standard CHC as at 31 December 2024

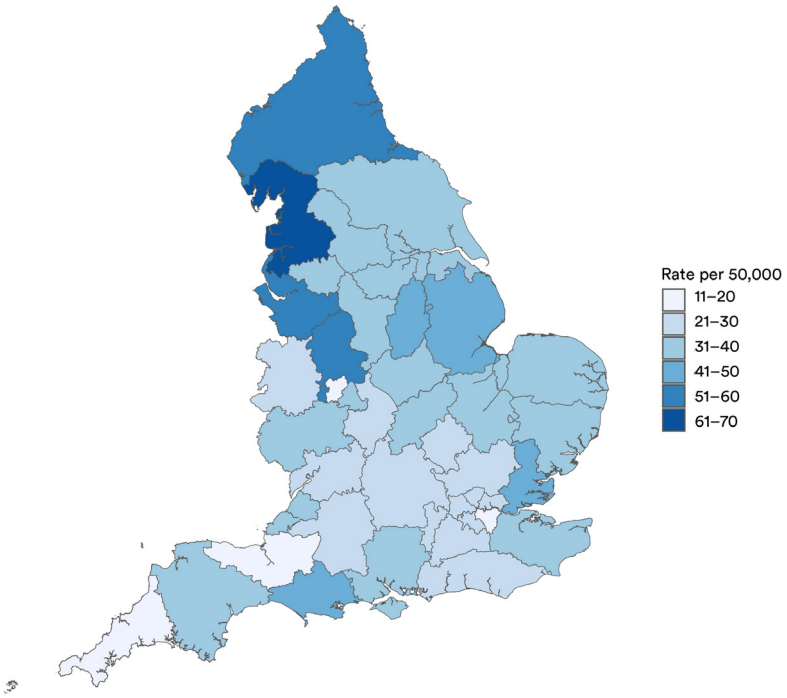
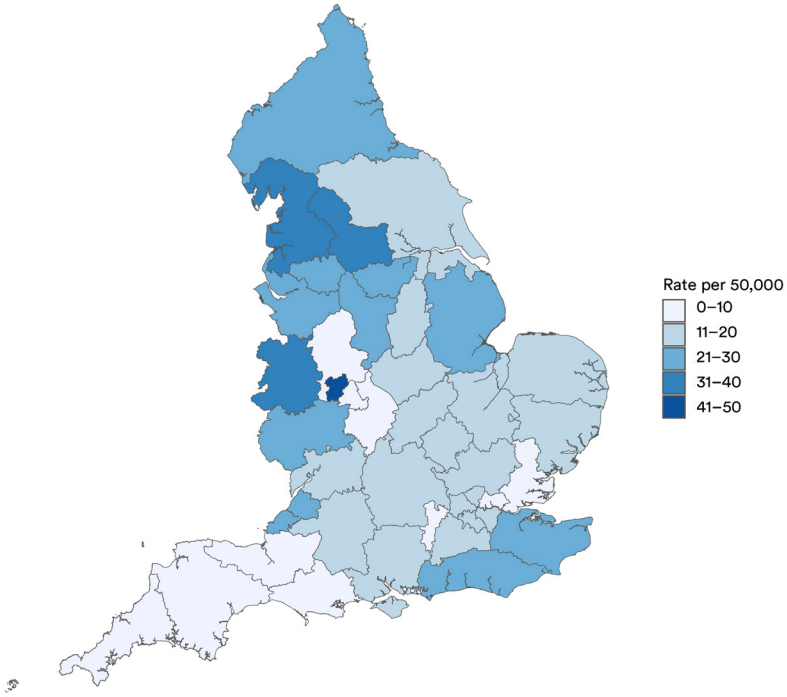


Figure 5: CHC eligibility rates per 50,000 adults for fast-track CHC as at 31 December 2024



Variation in the proportion of people newly assessed as eligible for standard CHC

Here we look at the **proportion of people newly assessed as eligible for CHC**. As illustrated in the national data, since the end of September 2017/18, all adults newly assessed for fast-track CHC have been found eligible. This means that those assessed for standard CHC are driving the variation in the proportion of individuals found newly eligible at assessment. In October–December 2024, the proportion of adults newly assessed as eligible for standard CHC varied across ICBs, ranging from 5% to 32%.

Over time, consistent with the national picture, 30 of the 42 ICBs have seen a fall in the proportion of adults newly assessed as eligible for standard CHC. Among these ICBs, the average proportion of people found newly eligible at assessment was 25% in October–December 2022, falling to 18% in October–December 2024.[43] However, 12 ICBs saw an increase in the proportion of adults newly assessed as eligible.

43 In-quarter data from Q3 2022/23 (October–December 2022) and Q3 2024/25 (October–December 2024).

5 Delving deeper: can local characteristics explain variation in CHC eligibility?

Key takeaway

- Our analysis finds that the level of deprivation and the proportion of people aged 75 and over in the population can explain some – but not all – of the variation between rates of adults assessed as eligible for CHC.

How does CHC eligibility vary by local characteristics?

We conducted analysis to explore the relationship between the number of people found eligible for CHC and selected proxies of need, including the age profile of the population and level of deprivation. These are by no means perfect indicators of need, but they do reflect known characteristics that describe areas with typically higher health care needs.[44] We wanted to explore the extent to which they explain the observed variation in eligibility for CHC.

We would expect higher levels of CHC eligibility in areas with greater need, such as areas that are more deprived and with larger older populations. We performed a linear regression model to test this hypothesis. We also

44 Appleby J, Raleigh V, Frosini F, Bevan G, Gao H and Lyscom T (2011) *Variations in Health Care: The good, the bad and the inexplicable*. The King's Fund. https://assets.kingsfund.org.uk/f/256914/x/2ceabe804.f/variations_health_care_good_bad_inexplicable_2011.pdf.

considered the relationship between level of urbanisation and CHC eligibility as we know there are unique challenges accessing health care in more rural areas (for instance, due to the geographical spread of services and limited transport options),[45] but this was not found to have a significant impact.

We found that both level of deprivation and the proportion of the population aged 75 and over were statistically associated with CHC eligibility. That is, sub-ICB locations with older and more deprived populations were more likely to have higher eligibility rates. But our regression model explained only a modest proportion ($R^2 = 0.24$) of the variation in eligibility rates across sub-ICB locations. This means that population age and deprivation cannot explain a large amount of the observed variation in eligibility for CHC.

The model found that the rate of adults per 50,000 found eligible for CHC increased 4.6 per 50,000 for each 1% increase in the proportion of the population aged 75 and over ($p < .01$). The number of people found eligible for CHC increased by 1.7 per 50,000 for each increase in deprivation score ($p<.01$). For more details on the model output and further analysis, including a comparison of predicted eligibility rates versus actual eligibility rates, see the Appendix.

While our analysis shows that deprivation and demographic structure can help to explain some of the variation in CHC eligibility between sub-ICB locations, it is evident that there are many more factors at play that are driving it. Chapter 7 – 'Luck of the draw: features and drivers of variation in CHC' – explores this further.

45 Public Health England (2019) *An Evidence Summary of Health Inequalities in Older Populations in Coastal and Rural Areas*. GOV.UK. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/824717/Health_Inequalities_in_Ageing_in_Rural_and_Coastal_Areas-Messages_and_summary.pdf.

6 Rising costs: how has spending on CHC changed over time?

Key takeaways

- Around £3.6 billion was spent on NHS CHC in 2022/23. After real-terms adjustment, spending grew 17.1% from 2017/18 to 2022/23. Fast-track CHC expenditure saw a real-terms increase of 55% between 2017/18 and 2022/23, driven in part by the growing numbers of individuals eligible for this type of care. The spend per eligible recipient rose for both standard and fast-track CHC.

- Spending on CHC is also not distributed equally. After adjusting for geographical differences in the cost of running services, the crude average spend per eligible recipient was lower in the fifth most deprived ICBs than in the fifth least deprived ICBs, and lower in areas in the north of England compared to the south.

Our analysis approach

- We sent a Freedom of Information request to NHS England on net NHS expenditure on CHC from 2017/18 to 2022/23, broken down by clinical commissioning group (in relevant years) and integrated care boards (ICBs). Note that this did not include expenditure on personal health budgets.

- We analysed how expenditure on CHC has changed over time in England, making a real-terms adjustment using HM Treasury's March 2025 Gross Domestic Product (GDP) deflators, rebasing figures to 2022/23 prices.

- We then compared the crude average spend per CHC recipient between different regions across England, and ICBs across different deprivation quintiles.

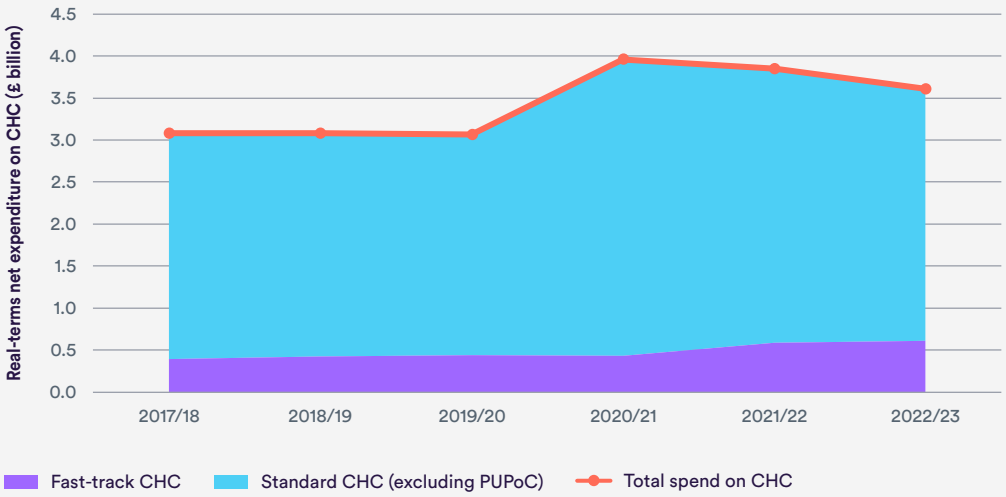
- We used NHS England's Market Forces Factor to adjust for differences in unavoidable costs to run services in different areas of England.[46] Unavoidable costs refer to costs that providers are unable to significantly influence, such as land, buildings and staff costs. The Market Forces Factor is not a perfect measure and does not adjust for factors such as social care provider availability; however, it does allow for a fairer comparison across areas in England.[46]

How much is spent on CHC?

Figures provided by NHS England show that expenditure on CHC – standard and fast-track – was £3.6 billion in 2022/23 (see Figure 6). Despite a steady decline in the number of people assessed as eligible for CHC, inflation-adjusted spending on CHC rose by 17.1% over the five years of available data from 2017/18 to 2022/23 – an average of 3.2% a year. However, the proportion of this growth between standard and fast-track CHC varied (see Figure 6).

46 NHS England (2023) '2023/25 NHS Payment Scheme A guide to the market forces factor'. www.england.nhs.uk/wp-content/uploads/2023/03/23-25NHSPS_Guide-to-the-market-forces-factor.pdf. Accessed 13 August 2025.

Figure 6: Total real-terms net expenditure on CHC (2022/23 prices)



Notes: Expenditure here is net NHS expenditure on CHC. It does not include expenditure on personal health budgets. PUPoC = previously unassessed periods of care.

Source: Nuffield Trust analysis of Freedom of Information request data from NHS England for 2017/18 to 2022/23, adjusted to 2022/23 prices using HM Treasury's March 2025 GDP deflators

Between 2017/18 and 2022/23, fast-track CHC spending increased at a faster rate than overall CHC spending, growing by more than 55% in real terms, likely reflecting the rising number of individuals qualifying for this type of care. Consequently, its share of total spending on CHC rose from 10.3% in 2017/18 to 13.8% in 2022/23. In contrast, spending on standard CHC grew at a slower rate, increasing by 11.6% in real terms over the same period. Standard CHC continues to account for the largest share of total CHC expenditure.

Although not included in published spending on community health care, expenditure on CHC is part of a bigger amount spent on community health and social care services. In 2022/23, NHS trusts spent £9.3 billion[47] on

47 Gainsbury S and Julian S (2024) 'Where does the NHS money go?'. www.nuffieldtrust.org.uk/resource/where-does-the-nhs-money-go. Accessed 4 August 2025. The figure cited in text has been adjusted to 2022/23 prices using HM Treasury's March 2025 GDP deflators. It will differ from referenced Nuffield Trust analysis, which presents the figure for community healthcare spending that was adjusted to 2016/17 prices using the April 2024 GDP deflator.

community health care and local authorities spent £23.7 billion[48] on adult social care (in cash terms).

As spending on CHC has risen and there has been a steady decline in the number of people eligible for CHC, the average spend per eligible recipient has increased for both standard and fast-track CHC. For standard CHC, the estimated spend per eligible recipient saw a 45% real-terms increase from £44,894 in 2017/18 to £65,185 in 2022/23 (2022/23 prices).[49] The spend per eligible recipient for fast-track CHC increased by a third, from £3,919 in 2017/18 to £5,225 in 2022/23 (2022/23 prices). Rising expenditure per CHC recipient may reflect a growing number of complex cases requiring more intensive or prolonged care. The significant difference in per-recipient spending between standard and fast-track CHC is likely due to individuals eligible for standard CHC tending to present with this complexity and needing care for longer periods of time than those eligible for fast-track CHC.

The sharp increase in spending in 2020/21 can be attributed to a surge in government funding for hospital discharges in response to the Covid-19 pandemic in order to discharge people quickly and prevent avoidable admissions.[50] This led to some individuals being directed to CHC without a prior assessment, or with assessments deferred. While spending has fallen gradually since the pandemic, it still remains above 2017/18 levels (real terms), suggesting that the cost of providing the same level of care has significantly grown.

48 NHS Digital (2023) 'Adult social care activity and finance report, England, 2022–23'. https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2022-23. Accessed 4 August 2025.

49 Estimates using total number in receipt of CHC at end of year 2022/23, taken from Q4 2022/23 (year to date).

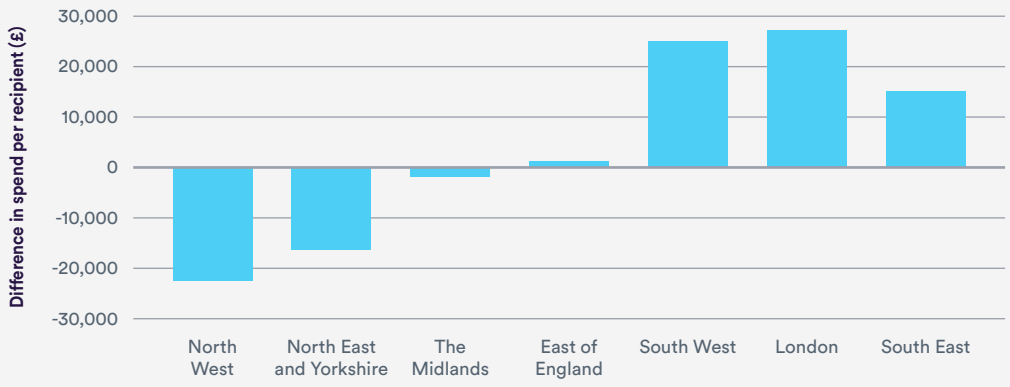
50 Department of Health and Social Care and NHS England (2022) 'Hospital discharge and community support guidance. Statutory guidance. www.gov.uk/government/publications/hospital-discharge-and-community-support-guidance

How does spending on CHC vary by ICB?

After adjusting for differences in unavoidable costs,[51] such as building and staff costs, in 2022/23, between ICBs the crude average spend per eligible recipient for standard CHC varied from £32,558 to £133,201 and as much as £1,668 to £27,360 per eligible recipient for fast-track CHC.[52]

Looking at regional variation, there was a clear divide between spending in the north of England and spending in the south of England. In 2022/23, a person found eligible for standard CHC in the North West had on average around £22,432 less spent on their care compared to the England average (see Figure 7). In contrast, people found eligible for standard CHC living in London had an additional £27,147 spent on their care compared to the England average.

Figure 7: Composition of regional differences in spend per eligible recipient for standard CHC relative to the England average (2022/23 prices)



Note: Expenditure here is net NHS expenditure on CHC. It does not include expenditure on personal health budgets. Area costs were adjusted using NHS England's 2022/23 Market Forces Factor.

Source: Nuffield Trust analysis of NHS England Freedom of Information data on spending on standard CHC by ICB, and NHS England's publicly available data on the numbers of people eligible for CHC (quarter 4, year to date, 2022/23)

51 Adjustments were made using NHS England's Market Forces Factor.

52 Estimates using the total number in receipt of CHC at end of year 2022/23, taken from Q4 2022/23 (year to date).

The regional variation in spend per eligible recipient for fast-track CHC was not as pronounced, likely reflecting the fact that people receiving this care will do so for shorter periods of time than those receiving standard CHC. Nonetheless, recipients living in the North East and Yorkshire on average received £2,567 less for their care compared to the England average, while a recipient in London received £2,030 more than the England average.

While we adjusted for unavoidable costs, this will not have captured all differences such as provider availability. The variation in expenditure by ICB will likely reflect provision of care as well as the quality of the data provided; it is possible that individual organisations interpreted the Freedom of Information request differently. Furthermore, the data do not include expenditure on personal health budgets, which may also affect total expenditure.

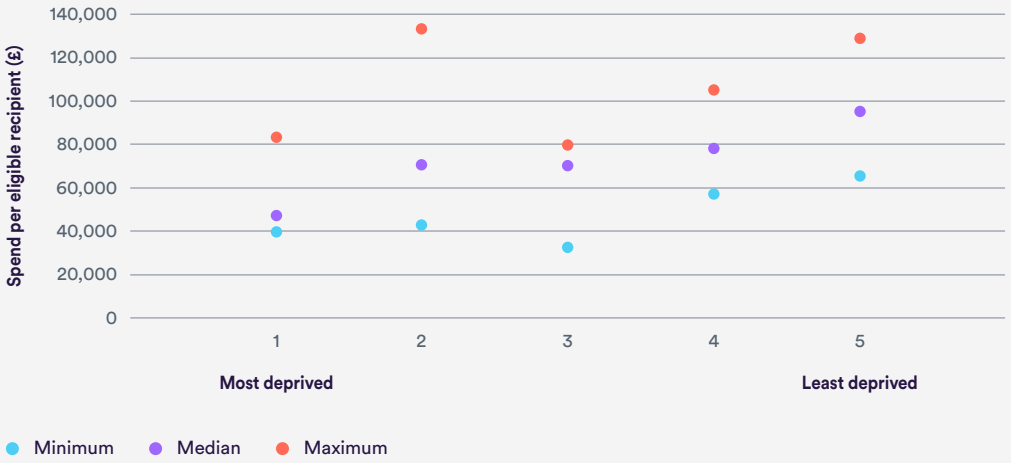
However, our analysis highlighted that, after adjusting for differences in regional unavoidable costs, spending per eligible recipient on CHC was lower in more deprived areas, although numbers of people found eligible for CHC is generally higher in these areas.[53] This pattern was more pronounced for spending on standard CHC where spend per eligible recipient was almost twice as much in the least deprived ICBs compared to the most deprived. Median spend per eligible recipient of standard CHC was £47,300 in the most deprived quintile compared to £95,085 in the least deprived quintile (see Figure 8). There is also likely to be significant variation in spend *within* ICBs.

As discussed in the previous chapter, more deprived areas tend to have populations with greater need after adjusting for age. It is not surprising, therefore, that ICBs are assessing more people as eligible for CHC in these areas compared to less deprived areas. NHS funding allocations to local areas include a specific component to direct additional funds to more deprived areas, to reflect unmet needs and higher avoidable mortality. This might lead us to expect higher CHC spending per head in deprived areas. While spending per head is only a crude average that does not take into account the duration of care packages, the contrasting pattern observed for CHC is concerning and suggests that an inverse care law is at play here. This may indicate that one way

53 Estimates using the total number of people in receipt of CHC at the end of year 2022/23, taken from Q4 2022/23 (year to date), and the Office for National Statistics'2019 Indices of Deprivation and Index of Multiple Deprivation.

in which ICBs manage finite health budgets and competing demands is to limit the scope of their CHC packages, and that this is happening more stringently in more deprived ICBs.

Figure 8: ICB spend per eligible recipient of standard CHC by deprivation quintile (2022/23 prices)



Note: Expenditure here is net NHS expenditure on CHC. It does not include expenditure on personal health budgets. Area costs were adjusted using NHS England's 2022/23 Market Forces Factor.

Source: Nuffield Trust analysis of NHS England Freedom of Information data on net expenditure on CHC by ICBs, NHS England's publicly available CHC data on the number of people eligible (quarter 4, year to date, 2022/23) and Office for National Statistics' 2019 Indices of Deprivation.

7 Luck of the draw? Features and drivers of variation in CHC

While our analysis suggests that patient and local area characteristics play a part in influencing NHS CHC assessments and eligibility, they cannot tell the full story. Our interviews and focus groups aimed to understand more about what variation in practice looks like at a local level and what factors are driving it. While we did not cover all issues exhaustively, the following themes emerged prominently in our discussions:

- local structures and processes
- commissioning and the provider market
- awareness and understanding of CHC
- relationships and integration
- resources and system capacity.

These were thought to influence not only variation, but also wider trends in access and eligibility.

Key takeaways

- Variation in CHC assessments and eligibility is complex and multi-faceted, influenced by several factors at individual, organisational and system levels. CHC teams and processes are organised and managed in a variety of ways locally, and integrated care boards (ICBs) also vary in their approach to commissioning and organising care for eligible individuals.

- Awareness, knowledge and understanding of CHC among the public and professionals are also a key driver. Several factors influence this, including the financial context, training and individual attitudes.

- Where CHC referrals come from is also important. For example, local services – such as residential settings, local authorities and acute hospitals – play a key role in identifying people in need of CHC and referring them. More generally, the nature of relationships and level of collaboration between NHS and local authorities, and the roles of individuals working in these organisations, are perceived to influence the effective operation of CHC.

- Additionally, funding, the financial context and capacity within the system are perceived to influence variation. This includes the financial pressures that organisations are facing and staffing.

Local structures and processes

How CHC is organised and managed at a local level

Although ICBs are legally responsible for CHC, what that looks like in practice differs across England. This includes the structure of their CHC teams, and their approach to assessments, commissioning and case management. Although this was not an exhaustive study of how every ICB approaches CHC, our work illustrated some of these different approaches, summarised in Table 3.

Table 3: Overview of how different ICBs approach CHC

Aspect	Examples of different approaches
Team structure	• Whole ICB or separate teams at a sub-ICB location level • Whether teams provide a service for people of all ages or for children/young people and adults separately
Accountability	• Which role is accountable for CHC within the ICB • Use of panels/boards to review care packages
Assessment and eligibility, case management	• Whether CHC assessment and eligibility are managed within the ICB or commissioned to other organisations such as providers or commissioning support units • Which data are collected and which system is used
Commissioning	• Whether ICBs have joint commissioning arrangements with local authorities • Use of Any Qualified Provider frameworks • Approaches to setting fee rates • Who is responsible for fast-track CHC services • Approaches to determining care packages (such as the use of high-cost care panels)

Source: Nuffield Trust analysis of interviews and ICB annual reports

In some cases, approaches to assessment and commissioning varied *within* ICBs, with some areas having five or more separate teams. Within this, there was variation in how teams were structured, for example whether they provided an 'all-age' service or whether adults' and children's services were dealt with separately.

The extent to which CHC was managed jointly with the local authority also varied and, in some areas, local authorities were more closely involved in the CHC process than authorities in other areas. This was often something that had evolved over time, with local authorities being more or less involved in assessments, to only being involved in commissioning and case management.

So one of the other areas in [the ICB], they have a social worker at every single assessment, DST [Decision Support Tool] review, whatever it is... So we've got a whole range of practices with our local authorities across [the ICB].
Interview participant – local authority

Application of the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care

Although there is a national framework for CHC – the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care – which sets out how the process should work, our research demonstrated a range of opinions over whether the framework was clear. Some participants thought that it was (and therefore there were clear parameters about whether certain people would be eligible for CHC or not) and that the challenges related more to a lack of awareness and understanding of the framework (and CHC itself) or inconsistent training. However, others considered that it was subjective and dependent on how the person's needs were evidenced. (It is worth noting that we did not test whether the interpretation of the framework was consistent between areas that felt it was clear.) Another aspect of this related to the historical context in which CHC had developed, with some participants considering that the framework was not fit for purpose for the nature of people's needs now, making it difficult to apply.

One of the common things that we find is there is quite clearly evidence that somebody has a primary health need. However, quite often it's terminology and how that evidence is produced and the detail behind that, that means that they don't get it. ... if... someone came in and spent a day supporting someone, they [would] quite quickly identify that yes, they do have that, those needs. But for care homes and yes, they have nursing staff... but [that] doesn't mean it's not a challenge to get your care staff and the senior care staff to be able to document things, sort of medical and clinical terminology, to ensure that you're triggering the right things on the checklist.
Focus group participant – care provider

In addition, participants provided examples of specific policies or practices around CHC assessments that they had observed in their local area (such as a refusal to conduct assessments for people already receiving NHS-funded nursing care despite changing needs, or for people in receipt of Section 117 funding), or where ICBs would only accept Decision Support Tool forms that had been completed by certain people or people who had undertaken specific training programmes.

> **In [parts of the ICB], trying to get a DST [completed] for some of our clients is very difficult. We get sent a paper to fill in. Then we get told it's not the right paperwork. Then we get told it's a different health professional that has to complete it. So we don't know from which patient that we're talking about, whether we're going to get that same service.**
> Focus group participant – care provider

Several areas had taken steps to improve the consistency of the interpretation and implementation of the framework locally. This included training for CHC teams, providers, social care staff and NHS staff. Two ICBs we spoke to noted that they had observed inconsistencies in how providers specifically were using the checklist, leading to targeted training for those organisations.

Patient factors

In addition to the impact of population differences (described in Chapter 5), patient factors were also thought to be influencing variation and access to CHC.

Demographics

National data published by NHS England do not currently report CHC by demographic characteristics such as age, sex and ethnicity, so understanding who is, and who is not, being referred, assessed or found eligible for CHC is difficult. While the NHS CHC Patient Level Data Set currently being rolled out

should mean that information is available in the future, for this report we have drawn on Freedom of Information data from individual ICBs.[54]

We sent Freedom of Information requests to all 42 ICBs to gather information on individuals eligible for CHC (both standard and fast-track) based on age, sex, ethnicity and health condition. The quality and consistency of the data we received varied across ICBs, and there were significant gaps in the information that ICBs collected and were able to provide to us. Table 4 provides an overview of responses.

Table 4: Overview of Freedom of Information responses

Characteristic	Total number of ICBs that collected data	Total number of ICBs that submitted data
Age	**37/42**	**24/37**
Sex	**37/42**	**23/37**
Ethnicity	**35/42**	**15/35**
Diagnosis type	**21/42**	**6/21**

Most ICBs collected data on age and sex, but there were notable gaps in the data on ethnicity. Eleven of the 35 ICBs that collect data on ethnicity reported either mixed quality and incompleteness – with only some areas able to collect the data within the ICB – *or* very large unknown populations. The most notable limitation included an unwarranted proportion of recipient ethnicities recorded as 'not known', 'not stated' or 'other'. The proportion of records with a valid ethnic group – records where ethnicity was stated – varied between ICBs, from a concerning 20% to 100%. Due to such a limited sample of ICB data that was available for our analysis, we were not able to understand the full extent of the potential barriers that individuals from specific minority ethnic backgrounds face in accessing CHC. Collecting information on ethnicity is

54 NHS England (2022) 'NHS Continuing Health Care (CHC) Patient Level Data Set'. https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/continuing-health-care-data-set. Accessed 1 August 2025.

essential for making meaningful improvements to ensure more equitable delivery of CHC, yet it remains a challenge for many organisations.[55]

In line with our finding that CHC eligibility tends to be higher in areas with older populations (see Chapter 5), of the 14 ICBs that were able to provide useable data on age by those eligible and aged either 18–64 or 65 and over, 12 reported a higher proportion of adults aged 65 and over assessed as eligible for standard and fast-track CHC than those aged 18–64 (total for 2023/24).[56] Two ICBs reported a higher proportion of younger-age adults found eligible for standard CHC compared to older adults, perhaps reflecting growing levels of need among working-age adults with life-long complex care needs and the overall demographic structure of these local areas.

Diagnosis

Few ICBs were able to provide information about clinical conditions – in several cases because it would require a manual review of individual care plans. Among those that could, each ICB codes conditions differently, making aggregating the data and looking for relationships challenging. It is concerning that most ICBs were unable to produce diagnosis data for us as it suggests that they, too, are limited in the insights they can draw and improvements they can make.

Despite the limited data, our qualitative work suggested that although eligibility is not based on diagnosis, people living with learning disabilities, complex mental health needs, frailty, and rare conditions were all thought to be less likely to receive CHC. Several participants were concerned that the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care was not suitable for assessing needs arising from dementia in particular. However, one participant reflected that this was reflective of a broader issue:

55 Scobie S, Spencer J and Raleigh V (2021) *Ethnicity Coding in English Health Service Datasets*. Nuffield Trust. www.nuffieldtrust.org.uk/sites/default/files/2021-06/1622731816_nuffield-trust-ethnicity-coding-web.pdf.

56 Although more than 14 ICBs provided data on age (see Table 4), some of the data was only partially complete or didn't provide exact specifications of what was covered in the information.

We find in our system and the health and care system that actually dementia completely falls between the cracks… It's not covered properly within CHC, but yet we've got an ageing population… we need to make sure that [the framework] properly accounts for those people living with dementia and what the demography of the future will look like and how we have to support them, because at the moment I don't think it does.
Focus group participant – provider

The concerns were not only about initial referrals for CHC but also about the assessment process, where a lack of understanding about the impact of a condition and how a person's needs manifest themselves meant that people may be less likely to be found eligible for CHC. This was further compounded if the person had multiple or complex needs. Some participants felt that the criteria in the Decision Support Tool were more easily evidenced for physical illnesses, with complexity arising from mental health needs (or where they interacted with other conditions) perceived as harder to evidence. Some providers had also witnessed an increase in virtual assessments, which they were concerned did not allow for a comprehensive review of a person's needs.

So people don't get very skilled in things like motor neurone disease, Huntington's… those… very different presentations across the same group of individuals with the same diagnosis…
Interview participant – ICB

Complexity

Participants also reflected more generally on changes they were observing regarding access to health and care services, and this was echoed in their experience of who was being referred or assessed for CHC. Several participants said that they were seeing complexity increasing, with people living longer with multiple complex conditions, coupled with an increasing desire or expectation for support to be provided at home or in the community. Several participants noted that they were observing this among working-age adults in particular.

Much more complexity and more volume of that complexity definitely. And there are a [number of] reasons for that… in terms of how the health care treatments have progressed, our ageing population, and also things like health inequalities all of that has affected the nature of people's needs who are being referred to health and care.
Interview participant – local authority

This complexity was also reflected in the care that people were being provided with. Several ICB participants noted that they were getting increasing requests for one-to-one support, which was not always considered appropriate, potentially resulting in people having unduly restrictive and expensive care packages they did not need. Some participants also mentioned that they had experienced issues relating to 'well-managed need', where people already receiving care might lose their CHC funding because their needs were being effectively supported. This was particularly concerning for individuals with complex behavioural needs – participants noted that their needs could appear *less significant* due to the appropriate support they were receiving. They emphasised that this did not mean the needs were non-existent and expressed concerns about the potential negative impact if such support was withdrawn. Some local authority participants noted that one consequence of this is that they are inappropriately (and unlawfully) supporting individuals whose needs the NHS should meet through CHC.

Some areas considered that people may be accessing alternative funded support – that is, not through the CHC process (although we were unable to identify through existing data sources who is self-funding their social care). One participant noted that their team started getting CHC referrals for individuals with learning disabilities after a service that provided similar care was decommissioned. Another reflected on the impact of locally commissioned services for people with mental health needs on CHC access, noting that while it may appear from data that there are fewer people receiving CHC funding, they could be receiving support in a different way. However, it is important to note that individuals who may be eligible for CHC should still be identified and assessed, even if other NHS-commissioned services are supporting them with their needs.

Adult mental health is generally an area when we look at population versus [those eligible for] CHC [and it] is generally an area where the ratio is quite low. And I think there's a number of reasons for that, some of which are that we commission services that support people in different ways and support people within their own home environment through our mental health trusts... I don't think it's representative of an unmet need. I think it's just representative of a differently met need.
Interview participant – ICB

Participants thought that the wider policy context was also driving the changes seen in access to CHC. This had resulted in more people being supported in the community who might have previously been cared for in hospital. Participants gave examples of increased use of supported living environments, which, while a positive development, had implications for the numbers of people who then required CHC funding. At the same time, there has been a continued policy focus on personalised care, which aims to increase people's choice and flexibility over how their care is delivered.[57] One way this has happened is through the introduction of personal budgets – everyone eligible for CHC, who receives care in their own home, is entitled to a personal health budget.[58]

Commissioning and the care market

Commissioning

In addition to the assessment process, ICBs varied in their approach to sourcing care packages for people eligible for CHC and the extent to which this was consistent across the ICB footprint. As of September 2024, we had identified 11 publicly available documents (such as a policy) that were easily accessible on ICB websites, which provided detail on their approach to

57 NHS England (no date) 'Personalised care'. www.england.nhs.uk/personalisedcare. Accessed 1 August 2025.
58 NHS England (no date) 'Personalised health budgets in NHS Continuing Healthcare'. www.england.nhs.uk/personalisedcare/personal-health-budgets/personal-health-budgets-in-nhs-continuing-healthcare. Accessed 1 August 2025.

commissioning. Most of these included key criteria or presumptions on which they would base their decisions, while also acknowledging the need to do this on a case-by-case basis. Some outlined a cost parameter for providing care at home and, if a care package cost more than that, alternatives would be sought. All acknowledged the need to balance individual choice and preferences with managing resources effectively, a challenge that was reflected through our qualitative work. In our interviews, we also heard examples of the use of panels to review high-cost care packages, or packages that fall outside costs parameters.

We did not set out to exhaustively examine the benefits or otherwise of using these policies or panels, but ICBs that used them considered that they:

- improved decision-making consistency
- provided greater clarity for patients
- led to better accountability for public money
- enabled a fairer and more equitable way of allocating resources.

Some of the ICBs we spoke to noted that they were undertaking work to standardise the approach to commissioning across the ICB in order to provide more consistency and transparency in their decisions. But there is a tension here in that the National Framework explicitly requires ICBs to use a person-centred approach, reflecting individual choice and preferences (in line with wider efforts to encourage personalisation through things such as personal health budgets).

There was also variation in the extent to which the NHS worked with local authorities to commission services, with some using formal joint commissioning arrangements, and pooled budgets. Where these joint commissioning arrangements existed, participants reflected that they were positive and helped to foster strong relationships at a local level, as well as more effective commissioning. Where formal arrangements did not exist, participants reflected on the importance of collaboration between the NHS and local government.

Setting fees and rates

Variation in the rates that NHS organisations paid emerged as a prominent theme in our research, although a range of opinions were provided in relation to this. In some areas we spoke to, the NHS approach to fee-setting for CHC-eligible individuals was aligned with how the local authority calculated rates for care. This was seen as important for ensuring consistency and reducing competition. In areas not already doing this, there was appetite for the NHS to move towards the approach as part of broader collaborative work with the local authority around commissioning and shaping the local care market.

> **We're almost competing against each other, but then equally saying that on the flip side, we don't want to become a cartel. And just all be the same. So it's how do we stimulate the marketplace?**
> Interview participant – local authority

While the Care Act 2014 places a duty on local authorities to engage in market shaping, the same does not apply to NHS organisations. But participants gave examples of efforts at a local level to improve the commissioning process, for example:

- introducing approaches to ensure greater consistency
- setting clear expectations
- ensuring good-quality provision.

This included developing more consistent provider specifications and frameworks, which had been co-developed with local providers and included embedded requirements around workforce, training and quality. Participants reflected that using these frameworks could help to improve consistency and transparency, as well as monitor quality. However, there was concern from providers that some types of framework (such as 'Any Qualified Provider') resulted in an "eBay-type service" for patients where providers were incentivised to provide care at the lowest rates in order for people to be placed with them, which was at odds with the need for care packages to be designed around the person.

Research participants provided further examples of good practice such as introducing brokerage and case manager roles who oversaw the commissioning process. These were considered to introduce greater consistency and foster stronger relationships between the NHS and care providers, as well as enabling others to focus on assessments and reviews. One ICB in its annual report noted that a key transformation objective was to move to an electronic referral portal, which would provide a single interface between providers and the CHC service.

More generally, a consistent challenge that participants from multiple provider organisations raised was that the fees do not reflect the realistic cost of care. Some providers noted that, in their area, the NHS was paying a similar rate to the local authority for care that was more complex. This was exacerbated by the fact that it is illegal for people eligible for CHC to use third-party top-ups, whereas this is possible for people whose care is funded by the local authority.

You can't charge third-party top-ups on CHC. And there's no self-funders on CHC. And yet, [NHS] insist on matching our local authority rates despite the criteria for CHC being intensive, complex, unpredictable, which by its very nature means higher staffing, higher dependency. So what we have got is real big-market problems because they [the NHS] are knowingly not funding the full cost of care.
Interview participant – local authority

This is reflected elsewhere. Recent research conducted by the Homecare Association identified not only variation, but also a significant deficit, in the amount the NHS paid for home care compared to local authorities.[59] This is important in the context of CHC. In response to our Freedom of Information request about the location in which people eligible for CHC were being

59 Houghton A (2023) *The Homecare Deficit 2023*. Homecare Association. www.homecareassociation.org.uk/resource/the-homecare-deficit-2023-pdf.html. Accessed 1 August 2025.

supported, 31 ICBs were able to provide some information, and in 17 of those, most people were being supported in their own home.[60]

Issues around the cost of care were highlighted as a particular challenge in specialist care settings that manage complex additional needs and challenging behaviours. As part of the Market Sustainability and Fair Cost of Care Fund, local authorities were required to conduct local cost-of-care exercises for care homes for people aged 65 and over and domiciliary care for people aged 18 and over, through surveying a range of local providers to improve their understanding of the actual costs of delivering care in their area.[61] But this exercise did not apply to NHS organisations, despite their role in funding and organising social care for CHC-eligible patients. Providers in our research reported a lack of engagement between them and the ICB, which led to challenges where the NHS had paid fees late, given no-fee uplifts or late uplifts. For providers, this reflected not only challenges with the rates themselves (and their ability to cover their costs), but also the lack of dialogue and communication between them and the NHS about what is an appropriate rate for care. In addition, providers reported variation in what CHC funding covered and the rate at which it was paid (such as for equipment or incontinence products).

How the contracts are calculated and then uplifted each year [is] certainly not as sophisticated at calculating individual fees as the local authority. I think probably because they [the NHS] do it slightly less… And then unlike the local authority, we have very little input into what happens each April when the contract prices are reviewed.
Focus group participant – care provider

60 Some provided a breakdown of figures across the ICB. Although we requested information relating to different settings, some areas combined responses (for example, nursing and residential care). Some also noted that they did not have access to information about the number of people being supported in a hospice. In 13 ICBs, most people were being supported in a nursing home.

61 Department of Health and Social Care (2024) 'Market sustainability and Fair Cost of Care Fund 2022 to 2023: guidance'. www.gov.uk/government/publications/market-sustainability-and-fair-cost-of-care-fund-2022-to-2023-guidance/market-sustainability-and-fair-cost-of-care-fund-2022-to-2023-guidance#cost-of-care-exercises--understanding-the-cost-of-providing-care-services. Accessed 1 August 2025.

Care setting and the care market

In addition to the setting of fees and rates, CHC can also provide insights into the availability of appropriate care settings. Our Freedom of Information requests asked ICBs to provide data on how many people eligible for standard or fast-track CHC were being cared for outside the area of the ICB, to get an indication of how many ICBs may be unable to access appropriate placements for people eligible for CHC within their area. Of the 19 ICBs able to provide data in response to this question, all were supporting at least one person eligible for standard CHC outside the ICB, with nine supporting at least 30 people. However, it is important to note that this does not include people who are supported within the ICB but – given the large geographical area that some ICBs cover – may be a significant distance away from their home or family.

Our interviews and focus groups also shed more light on issues with the care market. While some ICBs and local authorities considered that their local market was in good shape (especially with regards to residential care), several noted that they had particular challenges in their area. The most consistent challenge was the availability of good-quality nursing homes, or specialist settings that were able to cater for people with complex needs (such as people with dementia or complex behavioural needs). This meant that they had to place people out of area. This was reflected in ICB annual reports, with some ICBs highlighting the fragility of the local care market and an inability to fill care packages as a risk. While we cannot be certain, this could be a driver for the figures provided in the Freedom of Information responses.

Some participants also noted how there was a risk that if there was a smaller number of providers who provided specialist care, they could take advantage of the limited provision and charge higher rates to both the NHS and the local authority.

Awareness and understanding

Public awareness

During our interviews and focus groups, most participants pointed to different levels of awareness and understanding among professionals and the public about CHC, and how they affected variation. Participants noted that – like other aspects of health and social care – people who had someone who was able to advocate on their behalf (whether a relative, friend or professional) were more likely to be assessed or found eligible for CHC. This also applied in the context of local resolution – participants reflected that some family members and carers were unwilling to pursue resolution options despite evidence that the assessment outcome for their loved one may have been incorrect.

ICBs are responsible for raising awareness of CHC among their population and some ICB teams we spoke to gave examples of how they had attempted to do this.[62] This included:

- producing patient information leaflets (including in multiple languages)
- distributing materials to GP surgeries or hospitals
- attending community events
- assigning particular staff members to care settings
- creating a dedicated point of contact for the public.

One ICB reflected that this was harder to do since CHC had become something managed at ICB level, where it was perceived to be further removed from the local community. They had tried to counteract this by making CHC nurses more visible in particular services, such as nursing homes.

62 Department of Health and Social Care (2022) *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care*. GOV.UK. https://assets.publishing.service.gov.uk/media/64b0f7cdc033c100108062f9/National-Framework-for-NHS-Continuing-Healthcare-and-NHS-funded-Nursing-Care_July-2022-revised_corrected-July-2023.pdf.

So what they're doing is that the nurse is always visible, present and they can link a face to the service... So it's about raising the profile in that particular area of what CHC is... So we want to try and bring some of that community work back so the nurses have that assigned place that they can be visible and be seen.
Interview participant – ICB

Importantly, several people reflected that the challenges in access were likely reflective of broader challenges in access to health and social care services and were not necessarily specific to CHC. This included access to hospice care and social services. For hospices in particular, participants noted that there is still a lack of understanding about what hospices do and how they can help people, which required broader efforts to improve conversations about death and dying, and the support hospices can provide.

Staff awareness, experience and training

Several participants considered that the staff involved in CHC played a key role in influencing the outcome of CHC assessments. This included specialists', social workers' or nurse assessors' approach in individual assessments, and senior leaders working in ICBs or local authorities, and the knowledge or attitude they had towards CHC. This was felt to work both ways. Participants thought that it was important to have people with knowledge of the system who were able to "say the right things", "tick the right boxes" or generally advocate on behalf of the person at a system level and within individual assessments. Where staff had less knowledge or experience of using the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care, this could also impact the outcome. While the framework requires professionals who are knowledgeable of the individual's needs to be included as part of the multidisciplinary CHC assessment, several participants noted that, in their experience, often people involved in the multidisciplinary team did not seem to have the requisite knowledge of the person and their needs.

Potentially people... are ruled out [for eligibility for CHC] on the ability [or not] of the various different people in the MDT [multidisciplinary team] to argue their case, you know. And what you see is, the more skilled [the] MDT, the more people get CHC, the less skilled the MDT, the less people get the CHC – completely irrelevant of what the need is.
Interview participant – local authority

While this, in part, related to variable knowledge and understanding of the framework, it is important to note that some suggested that it was more down to individual attitudes. One participant reflected that this was also the case in adult social care more generally, where things could come down to a combination of personal perspectives and what had been 'custom' in a particular area. This was coupled with the perceived subjective nature of the national framework for CHC, where participants considered that the outcome for the person in need of care was often the result of the knowledge and skill of the person completing the documentation, as well as their personality and confidence to argue one way or the other. In addition, against the specific challenges of the financial context (described in more detail later in this chapter), the approach of assessors may also be directly affected by their awareness of those pressures, either informally or due to directions from the ICB itself.

It does seem a bit murky that it [is] based on what an assessor thinks on the day, sort of thing. And it's not always clear how that decision's reached. Despite the fact that there's a checklist, you can go through the checklist, you can appear to qualify for quite a lot of support and still not receive CHC funding. And the teams that are doing those assessments certainly seem to be very keen to avoid agreeing CHC funding because they know that they're under so much financial pressure.
Focus group participant – care provider

Beyond "saying the right things", participants noted that it was important for all staff to have knowledge and understanding of the CHC process and what is expected of them, particularly people working outside the NHS. This included how to fill in the necessary forms and evidence people's needs (including how this might vary for people with different health conditions), but also more practical things such as the need to attend meetings at short notice and respond to requests quickly. One participant reflected that their local authority had organised extensive training on CHC, which had helped social workers engage properly in the process, and collaborate more effectively with ICB colleagues, and this had had positive results.

Importantly, several participants considered that this meant access to CHC was based on "chance" or a "whim", dependent on the expertise or approach of the people involved in the assessment for CHC and whether services were able to proactively identify people who could be eligible. Providers reflected on examples where Person A was found eligible but Person B was not, despite having similar circumstances and needs, and there was a lack of understanding about why that was. This may be partly due to the wider lack of awareness and understanding of the CHC assessment and the criteria on which eligibility is based. This has significant implications for perceptions of fairness and consistency around how CHC is applied. We did, however, hear examples of good and holistic assessments, where assessors understood the person's condition, listened to those involved in their care and took account of all factors.

You can't have it [referrals] based on chance and [I] think a lot are by chance.
Focus group participant – care provider

Relationships, integration and accountability

Interaction with local services

Several participants referred to relationships between local services as a key factor in explaining the variation in referral and assessment rates, including between the local authority, acute hospital and other NHS provider organisations. Examples given of services where good working relationships are key included specialist services dedicated to supporting people with conditions such as stroke, motor neurone disease, learning disabilities or mental health. Where these services existed (and were "switched on" with regards to CHC), this was considered to play an important role. However, the existence and operation of these services at a local level are variable.

Some ICBs felt they were reliant on people being referred for CHC from other services, suggesting that it was incumbent on local authorities, care providers and community health care professionals to know about CHC and refer people appropriately. However, it was not clear that all areas were proactively monitoring this and – like access to social care more generally – without this, understanding the extent of unmet need is challenging. Aside from the role of specific individuals, participants spoke about whether there was a general awareness or culture within an area around ensuring that health care professionals in different health and care settings are proactive at identifying people who may be eligible for CHC.

[In our area] it's just second nature that you [the staff] know about CHC and you would be, every time they [staff] interact with a client who has approached adult social care, they will be looking at that – are there triggers here where this would need to go to a DST [Decision Support Tool]? It's so well embedded.
Interview participant – local authority

Some participants reflected on the variation in fast-track CHC referrals specifically, with some concerned that the need to discharge people from hospital quickly was driving this, resulting in people being inappropriately referred, who either did not require funding, or who should have been referred for a standard CHC assessment instead. The consequence of this was that either they suddenly had their funding withdrawn shortly after discharge or they were discharged to an inappropriate place (such as a hospice). One participant gave an example of a nurse based in a hospital whose role was to review fast-track referrals to confirm that they were appropriate and this had improved consistency in practice.

We share [multiple] acute footprints, which is always interesting... And from a fast-track perspective, we do see interesting things in terms of hospital discharge and use of fast track, but it's very different across the [respective] trusts.
Interview participant – ICB

In addition, participants reflected on the fact that end-of-life care services are organised and commissioned differently across England, which may go some way to explaining differences in fast-track CHC rates. For example, one hospice provider in our research had been commissioned by their ICB to provide palliative and end-of-life care services for everyone eligible for fast-track CHC, which they considered was a more effective and streamlined approach than looking at each case individually.

Relationships and integration

The relationship between the ICB and the local authority was also perceived to be a key driver in how CHC operated at a local level. Participants mentioned that this was particularly important when there was variation *within* an ICB. As well as different approaches to CHC (as described above), specific relationships or ways of working were seen as a significant factor in the variation observed. Where close relationships (and even formal joint arrangements) were in place, these were considered positive in ensuring collaboration and consistency at a local level.

If I go to [another local authority] as an example [in] the same ICB, it's the same senior management team in the ICB who grant that funding to [the other authority] but don't grant it to [us]. So what's the difference?... Some of it could be... just people and personalities and personality clashes and not being able to communicate in that sort of open way, working in partnership... They built those relationships, they've challenged, they pushed back. They've demonstrated that they know the legislation, the guidance, they know what they're talking about.
Interview participant – local authority

The wider relationship between the ICB and the local authority was noted as an important factor too. Where CHC was perceived to be working well, this was often down to close working relationships, effective communication and dedicated posts, with some areas already in or exploring more integrated or joint arrangements to a greater or lesser formal extent. This meant that individuals who were already receiving local authority support and required a CHC assessment were proactively identified and assessed. Participants referred to specific examples of collaborative working that dedicated posts had enabled, such as:

- social workers whose role was to work with the ICB
- dedicated CHC leads (or single points of contact) within local authorities
- ICB case management roles
- dedicated commissioning posts, with positive relationships between the NHS and care providers.

Dedicated commissioning posts were intended specifically to improve commissioning practices and encourage more collaborative and person-centred commissioning. A small number of participants referred to collaborative working in programmes outside CHC (such as Transforming Care – a programme designed to improve the lives of people with a learning disability and/or autism), which had helped foster trust and relationships and consequently affected practice around CHC in a positive way.[63]

63 Local Government Association, ADASS and NHS England (2017) *Transforming Care*. NHS England. www.england.nhs.uk/wp-content/uploads/2017/02/model-service-spec-2017.pdf.

I think that will be the fundamental reason for the differences across the country, to be honest. How hard have you pushed as a local authority and how hard [are] you prepared to push to get the right thing for your clients?
Interview participant – local authority

Participants thought that CHC acted as a bellwether for relationships at a local level, indicating the effectiveness of integration. Where there were challenges with CHC (and potentially several disputes), this had a damaging effect on relationships, which jeopardised wider integration efforts too. More generally, participants were concerned that instead of supporting integration, CHC reinforced a divide between the NHS and social care and that a wider lack of parity between the two was clearly visible in CHC too. Some local authority participants noted that even though CHC requires close working between NHS and local government, the fact that ICBs have the final decision on eligibility means it is a health-led process. This was compounded when CHC assessments were not conducted with the involvement of social care staff.

So, when we talk about integration… this [CHC] is one of the things that gets in the way because ultimately we end up in a kind of a really poor relationship around a particular framework, which has its flaws… but then when we get into conversations around the pieces of aspects of work that perhaps we want to engage on, I've got a thorn in my side, which is around, you know, I'm being done over and my residents have been done by the local NHS over affording people CHC so it is, it's quite destructive on an individual level, but I think also on a strategic level.
Interview participant – local authority

While previous research from the NHS Confederation suggested that the Covid-19 pandemic fostered better relationships,[64] it is not clear whether this remains the case. In the 2024 Association of Directors of Adult Social Services (ADASS) Spring Survey, 74% of directors reported that the number of disputes

64 NHS Confederation (2022) *NHS Continuing Healthcare: Delivering excellence*. NHS Confederation. www.nhsconfed.org/publications/nhs-continuing-healthcare. Accessed 1 August 2025.

over CHC funding that were escalated to local resolution had increased, up from 64% in 2023.[65] Our research suggests that local relationships are likely to influence this. Areas we spoke to that considered they had good and collaborative relationships felt that this meant disputes were less likely to occur, and one area had had no disputes in the past few years.

Accountability

Linked to relationships, participants felt that it is important that accountability mechanisms exist to ensure that people who may be eligible for CHC are referred and assessed appropriately. While individuals and families have some route to recourse through local resolution if they are dissatisfied with the process, local authorities and providers in this research were less confident about how ICBs were being held accountable for their approach to CHC overall, and whether NHS England was playing a strong enough role in relation to assurance across the system as a whole. This was thought to be especially important given the anxiety around the impact of financial pressures. Areas that were part of local or regional networks found these beneficial for comparing their experience to others and to gain peer support on how to approach challenging situations.

Our review of ICB annual reports demonstrated that several ICBs are taking action to improve accountability, governance and oversight at a local level (although we did not assess the effectiveness of these initiatives). This included:

- establishing quality oversight forums to oversee care packages
- consolidating CHC leadership
- establishing strategic groups chaired by an NHS senior leader with local authority representation
- using joint leadership models
- establishing pooled budget arrangements for CHC with local councils.

65 ADASS (2024) *2024 Spring Survey*. ADASS. www.adass.org.uk/wp-content/uploads/2024/07/ADASS-Spring-Survey-2024-FINAL-1.pdf.

Resources and system capacity

Organisational capacity

Several participants referred to variable resources and system capacity, which affected the number of assessments or reviews an area was able to complete, leading to delays or backlogs. Some acknowledged that when teams are facing significant pressures, reviews may be deprioritised, particularly if the person is in a place of safety. In some areas, external organisations (such as consultancies) had been brought in to undertake reviews on behalf of the ICB to tackle backlogs.

Participants also highlighted workforce pressures as a significant challenge facing CHC. This related to problems in recruiting and retaining nurses who act as assessors, and who have specialised in a particular area (such as learning disability). While nurse recruitment is a challenge across the NHS, participants highlighted that recruiting to CHC roles was particularly difficult due to:

- insufficient understanding of and training in CHC
- the challenging and hostile nature of some of the interactions and assessments for CHC
- low morale among staff.

Participants noted that they were increasingly unable to replace individuals who left, finding it difficult to recruit to permanent posts and having to deal with huge workloads. Some areas were relying on increasing use of bank or agency staff but acknowledged that these staff often have limited knowledge or experience of CHC. Workforce pressures were also identified in ICB annual reports, with one area noting that staffing shortages were a key cause of CHC review backlogs.

Not all areas viewed workforce as a problem and some specifically reflected that their team was long-standing, or that they had tried to address challenges by using permanent nursing posts with a higher Agenda for Change banding. Some had also explored training non-registered health care professionals to provide support, which had freed up nurse time to focus on assessments.

But they acknowledged they were still being increasingly asked to do more with less.

Financial context

A dominant theme throughout the research was the impact of the financial context and the realities of operating within such constrained resources, with several participants reporting that the financial context was a key driver in CHC decision making. While some referred to specific funding challenges facing individual ICBs and local authorities, others reflected more generally on the financial pressures in health and social care, which created a challenging backdrop to the operation of CHC.

Although many issues with CHC are long-standing, participants considered that they were exacerbated in the current financial context. Providers, ICBs and local authorities consistently raised budget constraints as a challenge, driven by:

- the increased complexity of people's needs
- the rising cost of care packages
- increased demand for care
- limited additional funding to support all this.

There were concerns that this resulted in 'cost-shunting' between the NHS and local authorities. This was reflected in several ICB annual reports, which identified CHC as a financial risk, a driver of deficit and/or an area where efficiency savings have been or need to be made, due, for example, to the increased complexity and cost of care packages noted above. Some participants referred to the fact that their area had a specific savings target for CHC that it had to meet, while others referred to more general expectations of savings across the ICB or NHS as a whole.

Some participants felt that these funding pressures were influencing the approach to CHC reviews in particular, resulting in more people being found ineligible upon reassessment. And there was an overall perception that it was also harder for people to be found eligible for CHC in the first place. There was particular concern about how this might affect decisions relating to people with high-cost or long-term packages of care. Several participants reflected on

the increase in the numbers of working-age adults in particular who required long-term care. Even if not explicit, there was concern that the potential of high-cost care packages lasting a long time could specifically impact decision making.

I think it comes from the centre. So I think the ICBs are just doing what they've been told to do. And again, if you look at the national data there is a downward trajectory now – that's not because suddenly we've got a different view of the CHC framework, how we interpret it. What we're doing is we're [trying to] fit the framework to a financial context.
Interview participant – local authority

These sentiments have been reflected elsewhere. In the 2024 ADASS Spring Survey, 95% of directors agreed that the tightening of the eligibility criteria for CHC meant that more care home placements (and their costs) relating to people with more specialist or complex needs were being transferred from the NHS to councils (or self-funders).[66] But ICB participants in our work also noted that the reverse could be the case too, reflecting on situations where they were seeing local authority-funded care being transferred to them.

You feel like from a kind of local authority perspective because those finances are quite stretched, they're potentially referring more people, to get that financial support elsewhere.
Interview participant – ICB

Instead of supporting collaboration, participants were concerned that the financial pressures placed significant strain on relationships, making it harder for ICBs, local authorities and providers to work together to design and deliver care for people who need it.

66 ADASS (2024) *2024 Spring Survey*. ADASS. www.adass.org.uk/wp-content/uploads/2024/07/ADASS-Spring-Survey-2024-FINAL-1.pdf.

The problem is when you're under a lot of financial pressure, and that's both for the local authority and the ICB, you're both looking to save money. It widens the gap rather than bringing you together. So what we should be able to do is look together to be able to think, actually, where we should be saving the money is in these people's needs being met appropriately. Are there other ways to meet needs? Can we work together to find a better way, reduce the level of support? But instead it becomes polarised and it's about you pay or we pay.
Interview participant – local authority

8 Putting things right: discussion and recommendations

We've got to get it right because it's so important... I think that's what makes it frustrating. It's the key to getting a lot right. But we've got it so wrong at the moment. The focus is in completely the wrong place.
Interview participant – local authority

Discussion

Why do our findings matter?

Continuing health care (CHC) provides a window into how our health and care systems work together – or perhaps more accurately, how they do not. CHC sits within a complex ecosystem of different accountability, funding and eligibility processes. It provides a prism through which to consider some of the fundamental issues at the interface of health and social care.

This report highlights the paradox that, despite overall demand for health and care being on the rise – driven in part by people living longer with multiple long-term conditions – the number of people eligible for CHC has fallen over time and varies significantly across England. While we found that some variation in eligibility for CHC reflects differing levels of need and differences between areas, there is significant unexplained variation. Our research suggests that a combination of factors – at individual, organisational and system levels – drives variation, including:

- inconsistent CHC practice
- differences in how much people know about or understand the process
- mounting financial pressures in health and social care, which are shaping local decisions about CHC.

The financial backdrop is no doubt challenging. CHC spend is rising, reflecting both the growing cost and complexity of care. Some integrated care boards (ICBs) are attempting to better manage finite resources through commissioning approaches that aim to make decisions in a more equitable way. But this creates a clear tension with policy ambitions for CHC to be person-centred, reflecting individual choice and preferences. ICBs have been asked to reduce their running costs by 50% by October 2025, with variation in CHC spend identified as a key area that needs addressing.[66,67] This exacerbates concerns that inadequate funding will drive decision making and risks more people losing out on the support they are entitled to.

People eligible for CHC are legally entitled to have their care paid for by the NHS, but our research suggests that people are not accessing support when they need it. The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care requires ICBs to ensure consistency in the application of NHS CHC, including using equality monitoring forms. But responses to our Freedom of Information requests revealed significant issues in the consistency and quality of data, highlighting concerning gaps in our ability to understand CHC access and provision, particularly for people from minority ethnic backgrounds. This made understanding potential disparities between people of different ethnicities in terms of access and provision almost impossible. There is also a gap in understanding around those who may be eligible for CHC but are never referred or assessed.

66 West D, Anderson N and Kituno N (2025) 'ICBs ordered to cut costs by 50%'. HSJ, 12 March. www.hsj.co.uk/policy-and-regulation/icbs-ordered-to-cut-costs-by-50/7038846.article. Accessed 1 August 2025.

67 Launder M and Anderson H (2025) '"Unaffordable" care spending driven by rush to clear hospital beds', *Health Service Journal*, 25 April. www.hsj.co.uk/integrated-care/unaffordable-care-spending-driven-by-rush-to-clear-hospital-beds/7039165.article. Accessed 1 August 2025.

While a small number of participants in this research had identified and were acting on potential inequalities, others recognised that their understanding was limited and that they needed to do more to proactively address inequalities for people from different backgrounds. A failure or inability to properly understand a population risks those in need being less able to access support, become more reliant on unpaid care and be more likely to present to services late, when their needs have become more advanced or complex.[68]

There is a clear mandate from NHS England for NHS organisations to proactively tackle inequalities in access to health care.[69] The National Healthcare Inequalities Improvement Programme identifies 'restoring NHS services inclusively' as one of its key priority areas.[70] This research raises significant questions about access to CHC, and it is important that NHS organisations consider this as part of their wider efforts to address inequalities.

At the heart of NHS CHC are individuals and their families who are faced with a complex and challenging process at the most difficult time, whether that is at the end of life or to have support with ongoing significant care needs. Our conversations with people who had been through the CHC process for their families demonstrated that not only is the assessment process itself challenging, but also the toll it takes is long-lasting, part of an ongoing struggle to access good-quality, timely care for their loved ones. Public awareness of social care and how it is funded is low.[71] Awareness of CHC and the assessment process is also low, and its existence can often come as a surprise to families who expect that their loved ones' care costs will be

68 Gainsbury S and Hutchings R (2022) *Review of the Mayor of London's Health Inequalities Test*. Nuffield Trust. www.nuffieldtrust.org.uk/sites/default/files/2022-11/1667818147_nuffield-trust-mayor-of-london-s-health-inequalities-test-web.pdf.

69 NHS England (no date) 'Our approach to reducing healthcare inequalities'. www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/our-approach-to-reducing-healthcare-inequalities. Accessed 1 August 2025.

70 NHS England (no date) 'Our approach to reducing healthcare inequalities'. www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/our-approach-to-reducing-healthcare-inequalities. Accessed 16 May 2025

71 Ipsos MORI (2018) *Understanding Public Attitudes to Social Care Funding Reform in England: Report prepared for The Health Foundation and The King's Fund*. Ipsos MORI. www.ipsos.com/sites/default/files/ct/publication/documents/2018-06/public-attitudes-social-care-funding-reform-ipsos-2018.pdf.

covered.[72] Coupled with variations in practice, the consequences for people and their families attempting to navigate this complex system are significant. The current system, which leaves individuals facing potentially catastrophic costs if they are not eligible for CHC, means the stakes are high – an 'all or nothing' approach that is problematic and does not reflect the nature of need. If individuals fall under the financial threshold during a social care means test, their local authority may be required to pay part or all of the costs of their care. But with both the NHS and social care under pressure to keep costs down and allocate resources equitably, people requiring care are caught in the middle.

What needs to be done?

A total rethink?

Many of the challenges we have identified in this research stem from the fact that health and social care operate as separate systems, with different funding streams and accountability structures. This research raises questions about the very existence of CHC and whether it perpetuates an in-built unfairness where some people's needs are supported but other people's needs are not. It highlights the importance of wider reform that creates a resilient and fair social care system that affords it parity of esteem with the NHS, enabling both systems to work alongside each other to support people.

But so far, comprehensive social care reform has been sorely lacking, despite repeated calls for action. Successive governments have repeatedly delayed and abandoned attempts at progress and reform. And instead, the sector has been shored up through sporadic injections of short-term funding, without an enduring long-term vision for change. Although social care is intended as a core partner in integrated care systems, there remains a mismatch between the status and resilience of health and social care services. Despite more than two decades of policy intent to better integrate services, people with complex needs that span both health and social care too often experience fragmented care. Nowhere is this more apparent than in CHC.

72 All Party Parliamentary Group on Parkinson's (2013) *Failing to Care: NHS continuing care in England*. https://chcfunding.wordpress.com/wp-content/uploads/2014/03/failing-to-care_appg-ful-lreport-2013.pdf.

The Casey Commission into adult social care offers a vital opportunity to start to build a strong social care system that can work alongside the NHS as an equal partner. In any reforms that follow, it is essential that supporting people with the most complex needs spanning health and social care domains is a central consideration. There is potential to learn from other countries where the demarcation between health and social care systems is effectively bridged through:

- clarity of entitlement to care
- consistency of the care offer
- crucially, the existence of a long-term care system that is supported through stable funding.

Urgent action

Notwithstanding the need for wider reform, action is required urgently to improve consistency and fairness in how CHC currently operates. While this would not address the fundamental issues, it is vital to ensure that the current system is operating most effectively for the people who need it now. Importantly, doing nothing is not an option. If the government is to make its ambition to shift care from hospital into the community a reality, addressing the problems in CHC will be an important step.

This research, including the stakeholder workshop, was conducted before the announcement that NHS England's functions are to be brought back into the Department of Health and Social Care[73] and the publication of the Model ICB Blueprint.[74] It is not clear yet what this means for CHC and where the various functions will sit. Nevertheless, this report underscores the importance of clear and decisive action to address variation in CHC, regardless of which national body is responsible. Our recommendations, which we set out below, are targeted at the stakeholder organisation responsible at the time of writing.

73 Department of Health and Social Care (2025) 'World's largest quango scrapped under reforms to put patients first', press release, 13 March. www.gov.uk/government/news/worlds-largest-quango-scrapped-under-reforms-to-put-patients-first. Accessed 30 July 2025.

74 NHS England (2025) *Model Integrated Care Board – Blueprint v1.0*. www.digitalhealth.net/wp-content/uploads/2025/05/Model-Integrated-Care-Board-%E2%80%93-Blueprint-v1.0.pdf.

Improving access to CHC and consistency in assessments

- **ICBs** should capture information on CHC assessments and eligibility by demographics and ensure that people completing equality monitoring forms alongside the Decision Support Tool receive training to effectively complete them. Particular action is required to address gaps in information and understanding about ethnicity.

- **NHS England** should use the information provided in the NHS CHC Patient Level Data Set to monitor access to CHC to identify gaps, and regularly report CHC eligibility by – at a minimum – age, sex and ethnicity, to proactively monitor and address potential inequalities in access.

- Drawing on examples of good practice and experience across England, **NHS England** should develop practical core training on the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care to ensure that key staff groups receive the same training, including how the framework applies to individuals with conditions such as dementia and learning disabilities. This should be co-produced with people with lived experience and include input from people with specialist expertise.

- **NHS England, ICBs** and **local authorities** should explore opportunities to spread good practice, share learning and encourage improvement and consistency. This could include identifying opportunities for peer reviewing or quality assuring assessments, and networks for information sharing, to develop a culture of continuous learning and improvement.

- **ICBs** should ensure that CHC assessments are conducted in line with the requirements of the National Framework, for example ensuring that a multidisciplinary team carries out the assessments – a team that includes health and social care professionals with knowledge and understanding of the individual and their needs.

- **ICBs** should proactively capture data and information on access to CHC assessments and eligibility, including where referrals are coming from, to understand gaps and address inequalities accordingly.

Improving commissioning practices and working with the care provider market

- **ICBs** should work with other partners within the integrated care system (including **local authorities** and **providers**) to develop approaches to commissioning that enable appropriate and personalised care for people with complex needs.

- **ICBs** should work collaboratively with other partners within the integrated care system to shape their local social care provider market. This could include agreeing consistent approaches to fee-setting (for example, the use of uplifts), which are appropriate for the type of care and level of need.

- **ICBs** should set out clear and transparent processes and policies for how they approach commissioning care for people eligible for CHC, ensuring these are publicly available and easily accessible.

Supporting integration and ensuring clear governance and accountability

- Given the recent announcements about the role of NHS England and the Model ICB Blueprint, there must be absolute clarity during the transition and an opportunity to consider carefully where responsibility and accountability for operationalising and overseeing CHC sit.

- All **ICBs** should have an easily accessible dispute resolution policy, which sets out the process for when a dispute arises between the ICB, local authority, care provider and/or the individual and their family.

- **NHS England** should review the effectiveness of local dispute resolution policies to identify whether these are working effectively and how learning is taken forward (including how this captures individual and family experience). This could include producing a national template to ensure consistency and reduce duplication.

- The **Department of Health and Social Care (DHSC)** should explore different approaches to funding for CHC, for example providing protected pooled budgets to ICBs and local authorities for people eligible for CHC. This is already happening in some places and learning should be harnessed. In addition, **DHSC** should undertake a robust evaluation of how

well these processes are working and whether they lead to improved outcomes for individuals, staff and organisations.

- **Local authorities** and **ICBs** should consider funding dedicated posts for people with expertise in CHC to provide a named point of contact to increase accountability and collaboration.

- The **Care Quality Commission** should incorporate CHC into its assessments as a way to explore its three key themes of: quality and safety; integration; and leadership.[75]

- Given the impact of the financial context and increased spending, the **National Audit Office** should update its previous work on CHC to investigate how CHC is funded and delivered and whether improvements can be made.[76]

75 Care Quality Commission (no date) 'Integrated care system assessments'. www.cqc.org.uk/guidance-regulation/integrated-care-systems. Accessed 1 August 2025.

76 Comptroller and Auditor General (2017) *Investigation into NHS Continuing Healthcare Funding*. National Audit Office. www.nao.org.uk/reports/nhs-continuing-healthcare-investigation/?nab=1. Accessed 1 August 2025.

9 Conclusion

NHS continuing health care (CHC) is a complex and opaque issue, often only raising its head in moments of crisis. But its existence goes to the heart of both the moral and practical debates about how we do – and should – fund and provide care for people with complex needs outside hospital. This research shows that there are significant issues facing CHC, which raise concerns about whether people can access support when they need it, and whether that support is provided fairly when they do. The huge financial and personal toll this can have on people, their families and carers is well documented. Given the trend towards people living longer with greater complex needs, including at the end of life, the issues of providing and funding long-term care are only going to become more important.

This research contributes to the evidence base on a complex and often poorly understood issue. We have particularly aimed to understand more about variation and how CHC is approached and managed in different parts of England, and the impact this has on who is – and who is not – able to access CHC funding. While variation is not a new issue, our analysis shows that unexplained variation persists, raising questions about consistency, fairness and transparency between and within ICBs.

CHC provides a window into some of the most fundamental issues facing health and social care. At the heart of CHC are individuals and their families who are faced with a complex and challenging process at the most difficult time. In the long term, comprehensive social care reform is essential, and the Casey Commission into adult social care, which should include CHC within its remit, will be valuable in moving this forward. But the commission is not set to report until 2028. In the meantime, urgent action is required to address the issues we have identified and improve CHC practice now, ensuring that CHC is delivered consistently and fairly across England.

Appendix: Detailed methodology

Our research for this report on NHS continuing health care (CHC) took place between May 2024 and June 2025. We used a mixed-methods approach and more detail on each method is provided below.

Document analysis

We began by reviewing the annual reports of all 42 integrated care boards (ICBs) (2022/23) to identify publicly available information on CHC experience locally. We then reviewed each ICB's website to identify any publicly available policies or information about the ICB's approach to CHC commissioning, identifying 11 documents. We analysed all of these and extracted information about ICBs' approaches and criteria.

Quantitative data analysis

Trends in CHC eligibility and assessments

For definitions on specific terms relating to NHS England CHC data, please refer to the 'NHS Data Model and Dictionary' for England.[77]

NHS England publishes quarterly snapshot data on CHC eligibility based on the financial year (April–March). We looked at data from 2017/18, the earliest year for which data is available. Due to inconsistencies in the population data published as part of the snapshot data, we recalculated rates for each quarter using NHS England's GP registrant data (for those aged 18+) for the middle month of each selected quarter.

77 See NHS (last published 31 March 2025) 'NHS Data Model and Dictionary'. www.datadictionary.nhs.uk. Accessed 6 August 2025.

We performed a paired samples t-test to compare average eligibility between the first two quarters and last two quarters of the financial year. We removed the Covid-19 pandemic year 2020/21 from the sample. There was a significant difference in average eligibility between quarters 1 and 2 (M = 54,762, SD = 1,879) and quarters 3 and 4 (M = 53,576, SD = 1,867); t(5) = 2.84177, p = 0.01809.

Expenditure analysis

NHS England provided us with data on net NHS expenditure on CHC and NHS-funded nursing care. These data do not include expenditure on personal health budgets. We calculated real-terms adjustments using HM Treasury's March 2025 Gross Domestic Product (GDP) deflators and we rebased figures to 2022/23 prices. We calculated adjustments for regional differences in unavoidable area costs using NHS England's 2022/23 Market Forces Factor.

Understanding variation in eligibility

Regression analysis

We looked at the following predictor variables:

- deprivation – the sub-ICB location Index of Multiple Deprivation (IMD) score is the weighted average of the deprivation score, described as the extent of deprivation in a given area[78]

- the percentage of the population aged 75 and over – this is the percentage of the GP registrant adult population aged over 75 in each sub-ICB location in July 2024 as published by NHS England.

Definition of the outcome variable

The outcome variable is the CHC eligibility rate – the number of adults eligible for CHC per 50,000 population (not age-standardised). We took quarterly snapshot data on the last day of September 2024 (Q2, 2024/25). We calculated rates using July 2024 GP registrant data. We removed two sub-ICB locations

78 Ministry of Housing, Communities and Local Government (no date) *The English Indices of Deprivation 2019: Frequently asked questions (FAQs)*. GOV.UK. https://assets.publishing.service.gov.uk/media/5dfb3d7ce5274a3432700cf3/IoD2019_FAQ_v4.pdf.

from the analysis due to missing data on either standard or fast-track CHC eligibility, or both. Table A1 presents the model statistics.

Table A1: Model output

	Dependent variable
	CHC eligibility rate per 50,000 population (standard error in parentheses)
Sub-ICB location IMD score per 1-point increase	1.673*** (0.329)
% of population aged 75 and over per 1% increase	4.627*** (1.027)
Constant	60.191*** (2.304)
Observations	103
R^2	0.243

Note: * $p < 0.1$, ** $p < 0.05$ and *** $p < 0.01$.

We rescaled the predictor variables to the mean. This means that the constant statistic represents the predicted eligibility rate per 50,000 population when the predictor variables are at their mean.

The model found that the proportion of the population aged 75 and over significantly predicted the rate of adults per 50,000 found eligible for CHC, with the rate increasing 4.6 per 50,000 population for each 1% increase in the proportion of the population aged 75 and over (95% CI: 2.59–6.66, $p < 0.01$).

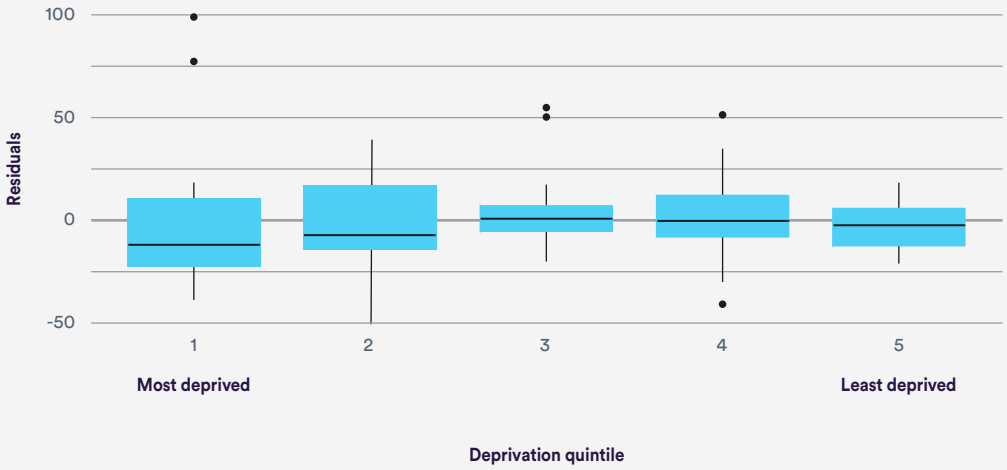
The model also found that the level of deprivation significantly predicted the number of people found eligible for CHC, increasing by 1.7 per 50,000 for each 1-point increase in the deprivation score (95% CI: 1.02–2.32, $p < 0.01$).

Overall, the model had a modest ability to explain CHC variability ($R^2 = 0.24$).

Residual plots

To understand how well the model predicts CHC eligibility across different levels of deprivation and to identify potential unexplained variation, we plotted the residuals by deprivation quintile (see Figure A1).

Figure A1: Residuals by deprivation quintile



While, on average, we saw a strong relationship between deprivation and CHC eligibility, we saw large variation in residuals in the most deprived quintiles, both shown in Figure A1. Figure A1 also shows that the model over-predicted eligibility for sub-ICB locations in these quintiles, indicating that potential unaccounted factors were driving variation, and that these factors were skewed to more deprived areas. In other words, eligibility rates were lower than expected in quintiles 1 and 2. This may suggest that some sort of 'protective' factor was at play or potentially need going unmet – that is, if other factors do not explain the variation.

Comparison of predicted CHC eligibility rates versus actual eligibility rates

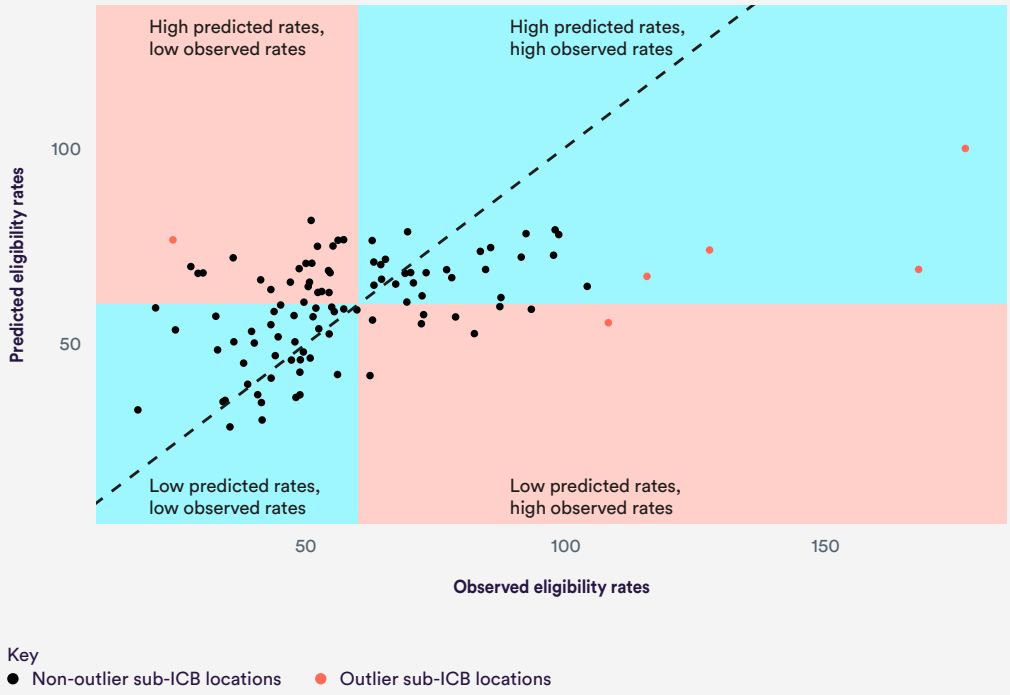
Given that variation in CHC eligibility rates was only partly explained by our chosen measures of need, we looked more closely at those areas that had a higher or lower level of eligibility than would be expected from the regression model. To do this, we compared the model's predicted eligibility rates for each sub-ICB location with actual eligibility rates.

When the predicted values are very similar to the actual values, the better the model is and the better the indicators of need we have included are at explaining the variation in eligibility rates. In other words, the model is successfully capturing the relationship between need and CHC eligibility. Where the model's predicted eligibility rates differ from actual rates, this

suggests that additional, unmeasured factors may have influenced variation in CHC eligibility. To understand the characteristics of the sub-ICB locations that fell outside the model's predicted values, we explored their geographical spread, which may indicate that organisational-level factors are influencing unexpected eligibility rates.

We plotted the actual eligibility rates of sub-ICB locations against the model's predicted eligibility rates (see Figure A2). We have grouped sub-ICB locations into quadrants to highlight those where actual eligibility rates were in line with those predicted, as well as those where predicted rates differed from those observed. Sub-ICB locations that are outliers as they followed no specific pattern are presented as red dots.

Figure A2: Scatterplot showing the model's predicted eligibility rates per 50,000 population against actual rates for sub-ICB locations



Note: Each dot represents a sub-ICB location. Quadrants in pink show the sub-ICB locations that fell outside the model's predicted eligibility. We defined outliers as sub-ICBs with a standardised residual greater than 2.

The means of the observed and the predicted were used as markers of the quadrants. The dotted line shows the line of perfect prediction. Outliers were identified by whether the standardised residual was above 2.

Understanding ICBs with lower eligibility rates than expected

The top left-hand quadrant of Figure A2 (high predicted rates, low observed rates) includes sub-ICB locations that had lower eligibility rates than expected. There are many reasons why this might be, but a closer look at these sub-ICB locations shows that they were located in different ICB locations across England. As these sub-ICB locations had lower eligibility rates than expected, this may suggest that additional factors were reducing the effects of deprivation and demographic structure on eligibility, or that some levels of need were going unmet.

Understanding sub-ICB locations with higher eligibility rates than expected

The lower right-hand quadrant of Figure A2 shows the sub-ICB locations that had higher eligibility rates than expected, suggesting that additional factors were leading to higher eligibility rates than those included in the model. This may reflect increased needs within these sub-ICB locations or more system-level factors playing a part. For instance, all bar one sub-ICB location were located in the Midlands and North West of England.

Understanding outliers

There were also several outlier sub-ICBs locations that did not seem to follow any predicted pattern. Five out of six of these sub-ICB locations had very high eligibility rates, all five were within the same region of England and four of them were located within the same ICB. This may indicate that ICB organisational level factors were influencing the higher-than-average eligibility rates. These sub-ICB locations were also among the most deprived.

Freedom of Information requests

We sent Freedom of Information (FOI) requests to both NHS England and all 42 ICBs in England. A summary of the questions is presented in Table A2. NHS England provided data on 7 May 2024. While all ICBs responded to our Freedom of Information requests, the amount and quality of the data were variable and we are unable to report on all of the questions.

Table A2: Freedom of Information requests sent to NHS England and ICBs

Organisation	Questions
NHS England	1. Please provide total NHS expenditure on NHS continuing health care (CHC) and from 2017/18 to the latest available in-year figure for 2023/24, broken down by clinical commissioning group (in relevant years) and ICBs. 2. Please make clear within the release how total expenditure has been defined – for example whether the figure provided is total net or total gross expenditure. 3. Where available, please also provide us with any subjective analysis that NHS England holds of national-level CHC expenditure for the period 2017/18 to 2023/24. We are not requesting this to be broken down at a local level, unless it is readily available in that format. 4. Where held, please include within any subjective analysis provided, national CHC expenditure by: • the following funding types: – standard CHC – fast-track CHC – NHS-funded nursing care • the following broad client groups: – working-age adults (18–64) – older adults (65+) • the following broad categorisations of spend: – cost of care packages – infrastructure, administration and staff costs – legal fees.
ICBs	1. Do you collect or hold data on the following? • The number of assessments and the number of individuals eligible for standard and fast-track NHS CHC by age (for example, date of birth). • The number of assessments and the number of individuals eligible for standard and fast-track NHS CHC by gender. • The number of assessments and the number of individuals eligible for standard and fast-track NHS CHC by ethnicity. • The number of assessments and the number of individuals eligible for standard and fast-track NHS CHC by patient diagnosis type. [We asked ICBs to complete a table with a 'yes' or 'no' in response to question 1 and if they responded 'yes' to any on the list, to specify the year from which data were available.]

Organisation	Questions
ICBs (cont'd)	2. If the answer to any of the above was 'yes', for each of the years from April 2017 to March 2024 please provide (by quarter): • the number of assessments and the number of individuals eligible for standard and fast-track NHS CHC by age, broken down into these age bands: 18–24, 25–34, 35–44, 45–54, 55–64, 65–74, 75–84 and 85+ • the number of assessments and the number of individuals eligible for standard and fast-track CHC broken down by gender • the number of assessments and the number of individuals eligible for standard and fast-track NHS CHC broken down by ethnicity • the number of assessments and the number of individuals eligible for standard and fast-track NHS CHC broken down by patient diagnosis type. Please provide the numbers for standard and fast-track CHC separately.
	3. Please provide the number of people who – as of 31 March 2024 – were receiving NHS CHC funding in each of the locations listed below, providing the figures for people receiving standard and fast-track CHC separately: • in their own home • in a residential care home • in a hospice • in a nursing home • other – please specify.
	4. Please provide the number of people who – as of 31 March 2024 – were registered in the integrated care system and were receiving NHS CHC funding outside the area covered by the system. Please provide numbers for standard and fast-track NHS CHC separately.
	5. Please provide total ICB (and, if possible, its predecessor – clinical commissioning groups) expenditure on NHS CHC from 2017/18 to the latest available in-year figure for 2023/24. Please make clear within the release how total expenditure has been defined – for example whether the figure provided is total net or total gross expenditure.

Organisation	Questions
ICBs (cont'd)	6. Where held, please provide, from 2017/18 to the latest available in-year figure for 2023/24, NHS CHC expenditure broken down by: • the following funding types: – standard NHS CHC – fast-track NHS CHC – NHS-funded nursing care • care packages for standard NHS CHC, broken down into these age bands: 18–24, 25–34, 35–44, 45–54, 55–64, 65–74, 75–84 and 85+ • care packages for standard NHS CHC by patient diagnosis type • cost of reimbursements for care following a successful appeal.
	7. For each of the years from April 2017 to March 2024, please provide the minimum, mean and maximum amount of time taken between a decision on eligibility and a care package commencing: • for standard NHS CHC • for fast-track NHS CHC.
	8. For each of the years from April 2017 to March 2024, please provide: • the number of requests made to your ICB (and previously clinical commissioning groups) for an independent review panel following a local review upholding a decision of ineligibility for NHS CHC • the number of decisions of ineligibility for NHS CHC made by your ICB (and previously clinical commissioning groups) that were overturned at the independent review panel • the number of decisions of ineligibility for NHS CHC made by your ICB (and previously clinical commissioning groups) that were upheld at the independent review panel.

ICB and local authority interviews

Using NHS England's CHC data we calculated the rate of people eligible for standard CHC per 50,000 population according to each ICB for the year to date until March 2024. We categorised these rates into three groups – low, medium and high – and invited for interview CHC teams within ICBs that represented a range of rates and geographical areas. Due to a low response rate, we eventually approached a total of 29 ICBs and interviewed 10 individuals from four ICBs.

To capture the views of people working in local authorities, we promoted the project and the opportunity to participate in it through the Association of Directors of Adult Social Services (ADASS) and its regional networks. We asked people to contact the research team if they were interested in taking part in an interview. In total, we spoke to 10 participants in seven local authority areas from a range of geographical regions.

We used a semi-structured interview protocol, which asked participants questions about:

- their approach to CHC (and relevant local context)
- perceived factors affecting variation in CHC
- access to CHC for different patient groups
- changes and patterns in CHC
- challenges in CHC
- areas of good practice
- action required.

Focus groups with care providers

To capture the perspectives of people working in care provider organisations, we held three online focus groups – on 5, 6 and 7 November 2024. The focus groups were promoted in the Nuffield Trust's newsletter and on social media, and through umbrella provider organisations. We promoted the opportunity to participate in them at a webinar that the Care Provider Alliance held in October 2024.

We asked interested participants to complete an online MS Form with their preferred session time and information about their provider, including: setting, turnover, primary population cared for, region, specialist area and whether they were a for-profit or not-for-profit organisation. We captured the characteristics only to ensure that our focus groups represented a range of perspectives. In total, 23 participants attended across the three focus groups. We asked the focus group participants about the same topics as the interviewees (listed above).

The focus groups were over-subscribed and those who were unable to join a session were sent a questionnaire containing the same questions covered in the focus groups. We received two responses, which we fed into the analysis. We also undertook one additional interview with a care provider.

Interview and focus group analysis

We used NVivo to conduct an inductive thematic analysis to identify key themes from the interviews and focus groups.

Workshop

We held an online stakeholder workshop on 5 February 2025 to share emerging findings from this research, sense check the findings and support interpretation. Eighteen participants attended the workshop, including representatives from the following organisations:[79]

- Age UK
- Association of Directors of Adult Social Services
- Beacon
- Care England
- Department of Health and Social Care
- Local Government Association
- National Audit Office
- NHS Confederation
- NHS England.

79 The named list above includes organisations who confirmed their attendance following the event.

At the workshop, we also conducted breakout discussions, where participants talked through required action in relation to four themes in greater detail, as listed below:

- assessment and eligibility
- commissioning and care provision
- integration
- wider reform.

This expert input fed into developing our recommendations. However, the findings of this report and our recommendations are the views of the Nuffield Trust and do not necessarily represent the views of workshop attendees or their organisations.

Limitations of this research

This research focused only on CHC for adults in England and did not explore the issues facing children and young people's CHC.

While all ICBs responded to our Freedom of Information requests, the amount and quality of the data we received were variable and we are unable to report on all of our questions – in particular, those relating to the time taken for care packages to be put in place and requests for local resolution and reviews. This partly reflects:

- the different processes that are in place at the local level in terms of data collection
- the complexity of data collection systems across ICBs
- difficulties in determining data accuracy.

Several ICBs noted that while they capture information we requested, providing it would exceed the time limit deemed appropriate for Freedom of Information responses.

While we sought to investigate the financial drivers of variation in CHC through quantitative data, we were unable to identify a suitable indicator of

the financial health of ICBs. As a result, our understanding of the underlying causes behind the trends in CHC is limited.

In the qualitative work, despite the rich insights we gleaned from it, we were only able to include perspectives from four ICBs. Although we sampled across numerous characteristics, given the levels of variation in approach to CHC, it is difficult to generalise our findings across the NHS as a whole. Similarly, we only reached a small sample of people working in local authorities and care providers. We acknowledge that although we aimed to speak to people in different parts of England, and from different settings, this was not necessarily representative of the huge range of perspectives and practices in different regions of England.

We also acknowledge that there is a risk of selection bias in the qualitative work in that people who had strong views (either positive or negative) may have been more likely to want to engage in the research. That being said, we identified a rich set of issues, which demonstrate the complexity of the topic and which highlight the need for further research.

Nuffield Trust is an independent health and social care think tank. We aim to improve the quality of health care in the UK by providing evidence-based research and policy analysis and informing and generating debate.

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