Parliamentary and Health Service Ombudsman

Continuing Healthcare: Getting it right first time

HC 872

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Foreword from the Ombudsman

"Our recommendations are rooted in the findings from the casework and point to essential changes that should be made to prevent similar failings for future care users."

NHS Continuing Healthcare is administered by local NHS Clinical Commissioning Groups (CCGs) with oversight from NHS England and NHS Improvement.

PHSO's casework has been instrumental in achieving improvements in the structure and processes of Continuing Healthcare for more than 25 years. This includes contributing to the development of the National Framework, which provides guidance about decision making.

In that tradition, this report draws on 60 cases resolved in the last three years relating to Continuing Healthcare. We have found not only significant failings in care and support planning but also failings in reviews of previously unassessed periods of care. The impact of these mistakes on people cannot be understated. They constitute an abrogation of basic rights. They have led to people unnecessarily paying out large sums to cover care, or going without care because of incorrect or delayed decisions. Many have faced years of uncertainty about their future finances and experienced stress, anxiety and ill-health as a result. The NHS should be supporting people in their care needs, not needlessly adding to emotional and financial burdens.

Our recommendations are rooted in the findings from the casework and point to essential changes that should be made to prevent similar failings for future care users. The recommendations are eminently practical and achievable in terms of shared learning and skills development.

Rob Behrens CBE
Ombudsman and Chair, Parliamentary and Health Service Ombudsman

Executive Summary

This report is the result of a detailed look at complaints PHSO has handled about NHS Continuing Healthcare (NHS CHC). The objective is to support those on the frontline of NHS CHC to learn from mistakes, improve quality, and consistently apply national guidance to deliver care packages that meet people's needs.

PHSO has published several reports on NHS CHC over the last 25 years, most recently in 2007, which contributed to the development of the National Framework for Continuing Healthcare and NHS-Funded Nursing Care[1] (the National Framework), first published in 2007.

We recognise that we publish this report into an NHS that is dealing with an unprecedented crisis in responding to the COVID-19 pandemic. This has had a major impact on the whole health and social care system, including on NHS CHC. The Government paused new assessments for NHS CHC and reviews of existing care packages between March and the end of August 2020[2] to allow the NHS CHC workforce to support hospital discharge arrangements thereby freeing up frontline staff to support the overall COVID-19 response. A move back into stricter lockdown measures may result in further pauses.

PHSO made decisions on 336 complaints about NHS CHC between April 2018 and July 2020. This report focuses on the two main themes we have seen in these recent complaints. Although this is a small proportion of the 112,000 people newly assessed as eligible in 2019-20, there are lessons for the system to apply to ensure NHS CHC meets the needs of the people who are entitled to it.

First, we explore what PHSO's casework tells us about the impact on patients, families and carers when Clinical Commissioning Groups (CCGs) have not carried out effective and inclusive care and support planning, and how this can be improved.

Second, we look at what PHSO's casework tells us about how CCGs have handled requests for reviews of previously unassessed periods of care. This involves CCGs looking back at someone's care needs in the past to decide whether they should have received NHS CHC-funded care at the time.

What we found – failings in care and support planning

We found that failings in care and support planning result in people and their families being forced to fund care, on top of that funded by NHS CHC. We also found that poor communication around care plans and packages can have similar outcomes, with people being unaware of their entitlements and the processes to challenge decisions where they believe shortfalls are occurring.

We found CCGs, with support from NHS England and NHS Improvement, need to make sure frontline staff have the skills and resources to deliver high-quality, comprehensive and inclusive care and support planning that meets individuals' care needs. We also emphasise the importance of good communication and involvement, so people are aware of what is covered in an NHS CHC package and how to challenge decisions about them.

[1] https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care

[2] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/911541/COVID-19_hospital_discharge_service_requirements_2.pdf

We make the following recommendations to help inform the ongoing continual improvement of NHS CHC:

Recommendation 1: Supporting the skills and experience of NHS CHC practitioners locally

CCGs should assure themselves that those involved in assessing care needs and developing care and support plans are appropriately skilled and experienced to perform that role by using the CHC Competency Framework. Regular training should be made available to frontline practitioners to ensure best practice is followed. At the least, CCGs should ensure frontline practitioners have undertaken learning from the NHS England and NHS Improvement e-learning tool to increase their knowledge and understanding.

Recommendation 2: Sharing learning nationally

In the short-term, NHS England and NHS Improvement should review the NHS CHC e-learning tool and other learning opportunities to ensure they take account of the learning from the case summaries included here. They should update these learning opportunities to ensure they provide effective support to the frontline NHS CHC workforce responsible for care and support planning and commissioning.

Recommendation 3: Putting learning into practice

In the long-term, NHS England and NHS Improvement should consider what additional support and coaching it can provide to care systems, CCGs and NHS CHC frontline staff to ensure they are appropriately supported and skilled in care and support planning and commissioning.

Recommendation 4: Supporting people and providers through the NHS CHC process

CCGs should ensure all parties to an NHS CHC-funded package of care are aware of the principles of NHS CHC funding and arrangements for additional services. CCGs should clearly explain in care and support plans what is included in the care package to meet the assessed needs, and the process that should be followed if any additional services or charges need to be considered.

What we found – failings in reviews of previously unassessed periods of care

We found that failings by CCGs when reviewing previously unassessed periods of care resulted in people waiting considerable periods for certainty about finances. We also found there was no detailed guidance to support CCGs in reviewing previously unassessed periods of care after 2012.

The learning from CCGs' failings in this area highlight the importance of high-quality and timely decisions that are communicated effectively with people who use services, their families, and carers. We make the following recommendations:

Recommendation 5: Developing national guidance

The Department of Health and Social Care (DHSC) and NHS England and NHS Improvement should consider the approach to previously unassessed periods of care dating from after 2012 and develop guidance to clarify CCGs' obligations. Guidance should set out explicitly how CCGs should respond to requests to retrospectively assess people's eligibility for NHS CHC-funded care such as Ms W's and Ms K's, whose requests relate to periods of time after the 2012 closedown. This guidance should make clear what CCGs' obligations are and give clear and specific timeframes for CCGs to meet these obligations. If deadlines for requests are imposed, these should be effectively communicated by CCGs to anyone who may have been affected to ensure no one is disadvantaged.

Recommendation 6: Delivering capability in the NHS CHC system

Once this guidance is in place, CCGs should assure themselves, with support from NHS England and NHS Improvement, that they have sufficient capability to successfully meet their obligations as set out in the guidance. Where assessments of previously unassessed periods of care are required by the guidance, CCGs should ensure they can complete timely and quality reviews.

Next steps

The learning in this report draws on the evidence from complaints to PHSO. The recommendations are practical and achievable, but we recognise the unprecedented pressures on the NHS due to COVID-19 mean that it may take longer than usual for them to be implemented.

We ask the Department of Health and Social Care, and NHS England and NHS Improvement to write to the Public Administration and Constitutional Affairs Committee and the Health and Social Care Select Committee in six months with an update on progress in planning and delivering these recommendations.

About PHSO

PHSO makes final decisions on complaints that have not been resolved by the NHS in England, UK Government departments and other UK public organisations.

PHSO looks into complaints where someone believes there has been injustice or hardship because an organisation has not acted properly or has given a poor service and not put things right. We do this impartially and independently of Government and our service is free for everyone.

PHSO shares findings from casework with Parliament to help it hold organisations that provide public services to account. We also share findings more widely to promote improvements in public services. PHSO is accountable to Parliament. Our work is scrutinised by the Public Administration and Constitutional Affairs Committee (PACAC).

Introduction

About this report

PHSO handles a significant number of complaints about a form of NHS-funded care known as NHS Continuing Healthcare (NHS CHC). Between April 2018 and July 2020, PHSO made decisions on 336 complaints about NHS CHC. This report highlights the learning from a sample of 60 cases. Ten of these cases are included as case study examples. These cases reveal important learning about the way CCGs have been applying national guidance about NHS CHC. We make recommendations to ensure the learning from these cases can be used to improve how NHS CHC supports people who need care and their families.

NHS CHC is administered by local NHS Clinical Commissioning Groups (CCGs) with oversight from NHS England and NHS Improvement.[3] In 2019-20, over 175,000 people were considered for NHS CHC funding, and over 112,000 people were newly assessed as eligible for NHS CHC. It is a complex and technical area of healthcare policy and decisions made under the policy can have a significant impact on the lives of care users and their families. This is why it is important that CCGs have robust processes for conducting evidence based, personalised care and support planning in line with the National Framework. CCGs also need to support people through this process with effective and inclusive communication, so they know what to expect.

The purpose of this report is to share the learning from our casework on care and support planning and previously unassessed periods of care with CCGs and NHS England and NHS Improvement to support and inform the ongoing and continued improvement of NHS CHC. We want CCGs to use the learning in this report to improve and act in line with the National Framework on care and support planning. NHS England and NHS Improvement should use the learning to understand what additional support CCGs may need to do this.

We want this report to contribute to the public knowledge of NHS CHC and help people understand what they are entitled to under NHS CHC. We also want this report to show the value and importance of giving feedback – including through complaints.

PHSO has reported on the complaints we receive about NHS CHC for over 25 years. Following one PHSO report in 2003 NHS funding for long term care: 2nd report - session

[3] Since 1 April 2019, NHS England and NHS Improvement have worked together as a single organisation. However, they remain legally separate entities. In this report, we refer to the single NHS England and NHS Improvement organisation, although some things remain solely the legal responsibility of NHS England.

This report highlights the learning from a sample of 60 cases. Ten of these cases are included as case study examples. These cases reveal important learning about the way CCGs have been applying national guidance about NHS CHC.

2002 to 2003,[4] the Department of Health[5] repaid £180 million to people who had to inappropriately fund their own care[6]. In 2007, the Department of Health issued the first national guidance for NHS CHC, creating a single framework and set of eligibility criteria for local commissioners to follow.

While this has improved NHS CHC, PHSO still sees a significant number of complaints where people have had to pay for additional care or were left with significant financial uncertainty. As a result, in 2017, we introduced specialist teams to consider our NHS CHC casework. This report is a result of the work these teams have done, and the deeper understanding we have gained as a result.

This report also includes an annex setting out in more detail how the NHS CHC system currently works, the challenges faced by the people using it over the past two decades, and the role that PHSO's casework has played in shaping improvements to address these challenges. We have included this background information in recognition of the improvements made by the NHS as a result of the National Framework, the complexity of

[4] https://www.gov.uk/government/publications/health-service-ombudsman-nhs-funding-for-long-term-care-2nd-report-session-2002-to-2003

[5] Throughout this report, we refer to the organisation by the name it had at the time. In this case, we refer to the Department of Health, which was renamed the Department of Health and Social Care in 2018.

[6] https://publications.parliament.uk/pa/cm200708/cmhansrd/cm080116/text/80116w0034.htm

NHS CHC policy and practice, and to inform readers who may not otherwise be familiar with the context in which PHSO has identified failings with the current system.

What we found

In developing this report, we have reviewed 60 of the cases we have completed in the last three years. Analysis of this casework has highlighted two key themes.

1. People being forced into 'topping up' care packages either because of errors in care and support planning, or because the CCG did not make them aware of what should be covered by their package or how to review or challenge the package. In two such cases, this resulted in significant financial and personal burdens being placed on people using care, their families and carers. The impact of this was so significant that PHSO achieved redress of over £250,000 for each family.
2. CCGs making mistakes when undertaking reviews of previously unassessed periods of care. These mistakes have resulted in people living with uncertainty for a considerable amount of time without knowing whether they or a relative were entitled to NHS CHC funding for their care.

In the cases we have seen, as well as the evidence provided by other organisations supporting people through this process, such as the CHC Alliance, it is clear that mistakes by CCGs have led to people unnecessarily paying out large sums to cover care or going without care due to incorrect or delayed decisions about NHS CHC funding. Others have waited many years with uncertainty about their future finances.

The impact of these mistakes on people cannot be understated.

Some people have had to find large sums of money to pay for their own care or that of their loved ones. In other cases where people have not been in a position to fund care, family members have had to step in to do this themselves. For one care user, this meant a family member being available 24 hours a day, seven days a week to cover their care needs.

In almost every case where this has happened, patients and their families have told us of the extreme stress and anxiety caused. This is, of course, in addition to the emotional and physical impact of the illness they or their family member have experienced.

People and their families entering the world of NHS CHC are already experiencing the stress and pain of complex care needs. CCGs need to be mindful of this and seek to support people eligible for NHS CHC in their care needs, and not add to the emotional and financial burden.

The impact of COVID-19

The COVID-19 crisis has put great pressure on the NHS. The Government paused new assessments for NHS CHC and reviews of existing care packages between March and the end of August 2020[7] to allow the NHS CHC workforce to support hospital discharge arrangements. This included freeing up frontline staff to support the overall COVID-19 response, such as hospital discharge activities and the transfer of staff to local providers to support discharge arrangements. Government also put in place emergency funding for people who would otherwise have gone through the NHS CHC screening and assessment process.

[7] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/911541/COVID-19_hospital_discharge_service_requirements_2.pdf

This pause was lifted on 1 September 2020. CCGs and their local authority partners are now working their way through these deferred assessments and also processing new referrals. CCGs must ensure people are not left waiting too long for decisions about their care, while still ensuring quality and fairness in care and support planning.

We will continue to monitor the complaints we receive to identify any learning that could support further improvement in NHS CHC, including any learning relating to the pause of NHS CHC assessments during the COVID-19 crisis of spring and summer 2020.

Getting it right first time: Learning from complaints

PHSO is the final step of the NHS complaints process. We can only look at complaints which have been looked at by the organisation complained about first. Although not the focus of this report, this means that all the complaints we have included here are the result of poor local complaints handling.

Complaints are a vital source of learning. PHSO's recent report Making Complaints Count: Supporting complaints handling in the NHS and UK Government Departments[8] sets out the findings from extensive research looking at the quality of complaints handling in the NHS. It shows the weaknesses of the current complaints system, with too much local variation in practice, a lack of training for staff and a culture where complaints are seen negatively.

The findings of Making Complaints Count have fed in to the PHSO's development of a Complaints Standards Framework.[9] This sets out a single set of standards for staff to follow and provides standards for leaders to help capture and act on the learning from complaints. It is built on the four principles of:

- promoting a learning and improvement culture
- positively seeking feedback
- being thorough and fair
- giving fair and accountable decisions

PHSO has consulted widely both in the development and draft of the Complaint Standards Framework, which was open for public consultation through summer 2020. The full framework will launch in 2021.

The Complaint Standards Framework will provide a consistent approach and support to frontline staff, as well as assisting senior leaders to promote a positive culture which embraces learning from complaints. It provides the basis for a central training platform for staff to give them the support and development they need, and to recognise

[8] https://www.ombudsman.org.uk/publications/making-complaints-count-supporting-complaints-handling-nhs-and-uk-government

[9] https://www.ombudsman.org.uk/organisations-we-investigate/complaint-standards-framework/complaint-standards-framework-summary-core-expectations

that handling and resolving complaints is a professional skill.

The importance of good complaints handling and using complaints as a source of learning can be seen throughout the cases in this report. The volume of complaints PHSO receives about NHS CHC shows that there is more CCGs can do to value complaints and use them to improve the services they provide.

CCGs and NHS England and NHS Improvement can use the learning from this report to ensure the NHS CHC system delivers quality and timely decisions, and supports people through a complicated and stressful time in their lives.

Complaints about NHS Continuing Healthcare

PHSO's casework has been instrumental in achieving improvements in the structure and processes of NHS CHC since our first report on this subject in 1994. Following PHSO's 2003 report on CHC, NHS funding for long term care: 2nd report - session 2002 to 2003[10], the Department of Health set aside £180 million to provide redress for people who were eligible for NHS CHC but instead had to pay privately for nursing care. Our work provided a unique source of learning that was also instrumental to the Department of Health developing the National Framework, which provides guidance that all CCGs must follow when making decisions about NHS CHC.

The National Framework has given people in need of NHS CHC and their families, CCGs, local authorities, care providers and PHSO a set of national guidelines about what people are entitled to and the responsibilities of the different organisations involved. The National Framework also makes clear that everyone faces the same eligibility criteria for NHS CHC, regardless of where they live.

Despite this, we still see many complaints about NHS CHC where CCGs have not acted in line with the National Framework.

Between April 2018 and July 2020, PHSO made decisions on 336 cases relating to NHS CHC. Of the 150 cases we investigated, we found failings in 55.

We were also able to achieve a resolution in 40 further cases without the need for a full investigation. We are increasingly working to ensure we get people the right decision at the right time when they bring a complaint to PHSO. Where we see that an organisation has made a mistake which could be resolved early on in the process, we will work with the organisation and the complainant to try and resolve the complaint without needing to undertake a lengthy investigation. This means we achieve a positive outcome for the complainant much sooner.

In this report, we focus on the two themes we have identified from reviewing these recently handled complaints:

1. Failings in care and support planning
2. Failings in reviews of previously unassessed periods of care

[10] https://www.gov.uk/government/publications/health-service-ombudsman-nhs-funding-for-long-term-care-2nd-report-session-2002-to-2003

Failings in care and support planning

Care and support planning is vital to understanding and meeting a person's care needs. From the CCG's perspective, care and support planning for people eligible for NHS CHC is an essential part of commissioning a care package and meeting an individual's assessed needs. It is mandated by the National Framework.

We have seen in several recent cases that too often care and support plans have not accurately identified a person's needs in full. For example, a woman with significant care needs who had been receiving 24-hour NHS CHC-funded care had her overnight care removed. This was an arbitrary decision by the CCG which was not backed up by its own evidence on her care needs. As a result, her family had to pay £33,000 from their own funds for overnight care until our investigation resolved the situation.

Sometimes, we have seen that a care and support plan has not been produced at all, meaning people have faced no choice but to self-fund some of their care. For example, one man received only a 15% contribution to his care costs from a CCG who had failed to produce a care and support plan. This meant he paid out almost £250,000 for care that should have been paid for by the NHS.

Others have had to draw on additional unpaid care and support from their families. For example, one family paid for private care and provided additional care themselves as a result of the CCG not producing a plan to support a woman to live at home. This CCG's decision to place an arbitrary cap on the level of NHS CHC-funded care meant her family paid for £187,000 of care privately and provided care worth a further £90,000.

Communication and involvement are central to a good, person-focused service. The National Framework is clear that the principle of personalised care[11] should be followed when developing an individual's care and support plan and commissioning their care. This is also a fundamental part of the NHS Constitution[12].

Some of the issues we have seen in relation to care and support planning could have been avoided with better communication about the NHS CHC process and what people should expect from a care package. People told us about the anxiety and stress they experienced as a result of the failings we have seen. NHS CHC is a complex part of the health and social care system, which people often access at a time when they are also under the stress and anxiety associated with managing their own or a loved one's poor health. CCGs should support people to understand NHS CHC, with clear and effective communication and processes for challenge and review. Better communication and involvement, in addition to providing more information about care packages and processes, allows CCGs to better manage expectations. It also allows CCGs to actively seek feedback and resolve issues quickly and efficiently.

The cases we have included here are ones in which families have managed to fund and provide care themselves when these costs should have been met by the NHS. But failings such as these could have much more devastating consequences for people who do not have funds to draw on. People may have to give up work to care for a loved one, or sell the family home to fund care. This can have hugely detrimental impacts on families, including on their physical and mental health.

[11] https://www.england.nhs.uk/personalisedcare/

[12] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/480482/NHS_Constitution_WEB.pdf

A further issue we have seen, as demonstrated in Ms F's story below, is where NHS CHC funding and a care package have been put in place, but the care provider then agrees additional charges directly with the family without the knowledge of the CCG. The National Framework sets out that it is the CCG's responsibility to make sure care providers are aware of the principles around additional charges. Where additional charges are proposed, the CCG should discuss this with the person using care to assure itself that the care plan and package is appropriate to meet their needs.

In Ms F's story, the CCG was unaware of the additional charges set by the care provider. Nonetheless, CCGs should make care providers aware of their responsibilities and the processes that should be followed if additional charges are sought. CCGs should also be making people and their families aware of the processes to review charges.

What the National Framework says

The National Framework sets out that the role of CCGs is to assess a person's eligibility for NHS CHC funding. Once eligibility is confirmed, the CCG must put in place an appropriate care plan and commission care provision. This must all be done with the involvement of the person, or their appropriate representative.

Care planning and delivery

165. Where an individual is eligible for NHS Continuing Healthcare, the CCG is responsible for care planning, commissioning services, and for case management. It is the responsibility of the CCG to plan strategically, specify outcomes and procure services, to manage demand and provider performance for all services that are required to meet the needs of all individuals who qualify for NHS Continuing Healthcare. The services commissioned must include ongoing case management for all those eligible for NHS Continuing Healthcare, including review and/or reassessment of the individual's needs.

166. CCGs should operate a person-centred approach to all aspects of NHS Continuing Healthcare, using models that maximise personalisation and individual control and that reflect the individual's preferences, as far as possible, including when delivering NHS Continuing Healthcare through a Personal Health Budget, where this is appropriate.

Figure 1: National Framework for Continuing Healthcare and NHS-Funded Nursing Care

The National Framework is clear that, once eligibility is established, a care package must be in place to meet all of an individual's assessed health and social care needs as identified in the care and support plan. Personalisation is a core principle, ensuring that an individual's preferences are reflected. The National Framework acknowledges that sometimes people might want additional voluntary services outside of the care and support plan. For example, for people living in

a nursing home, this might include services like hairdressing or nail care that are provided at the same location.

The National Framework stipulates that all additional services and charges should be clearly identified. Crucially, it also says that the CCG should discuss with the person or family why they feel they require additional services, to make sure the NHS CHC package is sufficient to meet the person's assessed care needs in full. The CCG should also ensure the care provider is aware of these principles and refers any request for additional services to the CCG for consideration.

The National Framework gives CCGs and practitioners clear roles. NHS England and NHS Improvement has also developed an NHS CHC e-learning tool[13] to support those working at the frontline to meet their responsibilities.

What our casework tells us: failings in care and support planning

Mr S's story

Mr S suffered severe brain damage as a result of a clinical incident in 2002. He returned home from hospital in 2005, with his care funded through NHS CHC. He pursued a clinical negligence claim and, in 2010, he was awarded a financial settlement from the hospital Trust, leading to annual payments. This settlement included private healthcare for seven hours a week.

In 2012, Mr S's deputy[14] wrote to the CCG to forfeit his NHS CHC funding and opt for private care, paid for from his personal injury settlement. The deputy negotiated with the CCG to pay 15% towards the cost of Mr S's care. This was a mistake by the deputy.

In 2014, Mr S changed his deputy. The new deputy asked the CCG to reinstate the NHS CHC funding. The CCG reviewed Mr S's eligibility in 2014, finding him eligible for full NHS CHC funding. However, over the next five years, Mr S was unable to secure the NHS CHC-funded care he was entitled to, after a series of failings by the CCG.

The CCG failed to produce a care and support plan and did not put funding in place for Mr S's care. The CCG continued to pay only the 15% contribution to Mr S's care costs, leaving Mr S to carry on funding his own care.

Mr S's deputy kept asking the CCG to reinstate the full NHS CHC package. As a result, the CCG reviewed Mr S's eligibility again in 2016, once more finding him fully eligible for NHS CHC funding. The CCG again failed to prepare a care and support plan to understand his needs and did not put in place the full NHS CHC funding package, only paying the 15% contribution to his care costs.

After Mr S's deputy made further complaints to the CCG, in November 2017 the CCG agreed to take on full responsibility for Mr S's care package. It also agreed to reimburse him for the care he had paid for, dating back to the review in December 2016. It refused to reimburse him for the period dating back to 2014, even though the CCG itself had previously said that Mr S was eligible for NHS CHC funded care since that date.

When Mr S brought his complaint to PHSO through his deputy, it was clear to us in the

[13] https://www.england.nhs.uk/healthcare/nhs-ch/

[14] A deputy is someone who can make decisions on behalf someone who is not able to make decisions themselves, for example because of a mental or physical impairment https://www.gov.uk/become-deputy

early stages of looking at the case, that the CCG had not put in place a care and support plan, as mandated in the National Framework. If the CCG followed the National Framework when it found Mr S eligible for NHS CHC in 2014, it would have put in place a care and support plan and sourced an appropriate care package.

We worked with the CCG to achieve a resolution for Mr S without the need for a full investigation. Our intervention led to the CCG agreeing that it should have put in place a care and support plan and NHS CHC funding for Mr S from 2014. The CCG agreed to reimburse Mr S for the care he had paid for privately, for the full period between 2014 and 2017. This totalled approximately £250,000.

By working with Mr S and the CCG early on in PHSO's process, we provided a positive outcome for Mr S and valuable learning for the CCG. Mr S has now finally been awarded the funding – and the care – he was entitled to.

Ms F's story

Ms F was receiving NHS CHC-funded care at a residential nursing home. The CCG had agreed with the care provider to pay the standard fee.

The care provider subsequently agreed an additional care fee directly with the family. The contract for this additional fee explained it was not for any additional voluntary charges, such as the use of telephones, newspapers, hairdressing, private health care. The CCG was unaware of this additional charge.

It therefore appeared that the family were paying an additional charge for Ms F's care. Although there are some types of services that a person may wish to use that would not be funded by NHS CHC, the National Framework places responsibility on the CCG to consider any 'top-up' services to assure itself that the care and support plan and package are appropriate for the person's assessed care needs. This means that the CCG must consider any 'top-up' services first before the care provider charges someone for these additional services.

In Ms F's case, the CCG did not have the opportunity to consider whether the additional services Ms F wanted to use should have been NHS CHC-funded. This is contrary to the National Framework. However, the CCG did not review the contract in response to the complaint made by Ms F's family.

Following our intervention, the CCG agreed to review the contract between the care provider and the family and make sure that the NHS CHC care package met the care needs of Ms F in full.

Ms E's story

Ms E suffered a stroke in 2016. She was assessed and found eligible for NHS CHC funding, with the assessment finding she needed the assistance of two carers at all times to support her daily living and keep her safe. The CCG found that Ms E's needs would best be met in a 24-hour care setting.

Ms E's family wanted her to be cared for at home. The CCG offered a care package equivalent to the cost of a nursing home placement plus 10%, which resulted in the CCG providing enough funding for one carer for seven hours a day. This meant the family had to provide additional care themselves, as well as paying privately for extra care.

The family complained about the care package. They submitted a record of the additional care costs they had incurred. The CCG reviewed Ms E's NHS CHC eligibility two more times, both times finding she remained eligible for NHS CHC-funded care.

Despite this, the CCG did not produce a care and support plan setting out what Mrs E's care needs were. As a result, it continued to fund only one carer for seven hours a day, even though it had said that Ms E needed support from two carers at all times.

The CCG had a policy that it would only fund care at home up to the cost of nursing home care plus 10%. However, in this case, the policy was wrongly applied. The CCG used the arbitrary figure of a standard nursing home placement plus 10% to determine the level of care. The CCG did not compare costs of a nursing home placement with the costs of care at home to fully understand the cost of care in each potential setting and determine the funding needed to provide the level of care Ms E needed.

We found the failure of the CCG to produce a full care and support plan meant that Ms E's care needs were not met by the care package it put in place. These failings had a profound impact of Ms E and her family. They were forced to pay for additional care, as well as provide additional care themselves.

We recommended that the CCG reimburse all the professional care costs incurred by Ms E's family, totalling approximately £187,000. We also recommended the CCG reimburse the family for the care they provided to Ms E, totalling a further £90,000.

Ms P's story

Ms P was provided with overnight care as part of her NHS CHC package from the start of 2017. In mid-2017, the CCG decided to remove the overnight care from the care package and instead provide additional care during the day. The CCG did not discuss this change with Ms P's family. The CCG said it made this change because Ms P was no longer waking up during the night and she had not required any night-time care since she started using NHS CHC-funded care.

A review completed by the CCG's NHS CHC practitioners after the removal of overnight care showed that Ms P still needed 24-hour care. Despite this evidence, the CCG decided that the overnight care was no longer needed.

We found that the CCG failed to discuss the changes in Ms P's care provision with her family. It also failed to discuss and implement a suitable care and support plan to ensure Ms P's care needs could continue to be met. It did not undertake a full review of Ms P's care needs. As a result, Ms P's family paid privately to ensure her overnight care needs were still met.

Ms P's family told us that this experience was extremely distressing for them, as they were forced to pay privately to make sure she received the care she needed.

We recommended the CCG repay the cost of the care Ms P and her family had arranged following the removal of the night-time care. This totalled approximately £33,000.

Conclusions and recommendations

In addition to the individual cases we highlight in this report, we have examined the findings of others to understand why flaws remain in the care planning process. For example, organisations like the Continuing Healthcare Alliance (CHC Alliance) have suggested there may be a disconnect between the National Framework and frontline NHS CHC practitioners.[15] This can mean that those at the frontline charged with care planning may struggle to bring the relevant members of a Multi-Disciplinary Team (MDT) together,[16] or may themselves lack experience, leading to mistakes.

[15] https://445oon4dhpii7gjvs2jih81q-wpengine.netdna-ssl.com/wp-content/uploads/2018/01/Effective-commissioning-approaches_Br1718-v3_WEB.pdf

[16] https://www.parkinsons.org.uk/sites/default/files/2017-08/cs2332_continuing_to_care_leavetoexperts.pdf

In 2016, the CHC Alliance also suggested[17] a national training programme for frontline NHS CHC staff.

The NHS CHC Strategic Improvement Programme[18] that is running from April 2017 until March 2021 has led to the development of the NHS CHC e-learning tool[19] and the CHC Competency Framework for frontline staff in CCGs. Apprenticeships schemes and a level 7 Open University qualification[20] are in development.

It is crucial that CCG staff undertaking care and support planning do so with the appropriate support, tools and expertise required. Not doing so risks people not receiving the care they need or families paying large sums, and potentially taking on financial risks, to ensure care needs are met. It also risks placing additional pressures on CCGs as they manage additional complaints and reviews when they do not get it right first time.

While there are CCGs who will get this right and be supporting their workforce's skills and capability, all CCGs must assure themselves that staff involved in NHS CHC assessments, care and support planning and commissioning are appropriately skilled and experienced to deliver the quality and evidence-based actions people have the right to expect.

It is also good value for money for CCGs to make consistent and correct NHS CHC decisions and actions. NHS CHC assessments are a resource intensive process. Getting it right first time ensures workforce capacity is not impacted by unnecessary reviews and subsequent complaint handling. These take attention and resource away from making good quality assessments and care and support plans, and ensuring people get the care they need.

2020 has presented the entire NHS with unique challenges as a result of the COVID-19 emergency. New NHS CHC assessments were paused from March to 31 August, and frontline

[17] https://www.parkinsons.org.uk/sites/default/files/2018-04/CS2332%20Continuing%20to%20Care_Report_Hyperlinks.pdf

[18] https://www.england.nhs.uk/healthcare/nhs-chc-strategic-improvement-programme/

[19] https://www.england.nhs.uk/healthcare/nhs-ch/

[20] Level 7 qualifications are the equivalent of a master's degree https://www.gov.uk/what-different-qualification-levels-mean/list-of-qualification-levels

staff redeployed. This has resulted in a number of deferred NHS CHC assessments for CCGs to work through. While it is imperative for CCGs to undertake each assessment in accordance with the National Framework, it is also vitally important that the deferred assessments are dealt with efficiently so people are not left waiting for long periods of time without certainty about care provision. CCGs must not divert attention and capacity from this.

Alongside addressing the immediate challenge posed by the deferred NHS CHC assessments, NHS England and NHS Improvement and CCGs should work together to ensure the workforce is appropriately supported, skilled and experienced to conduct assessments effectively and develop accurate and comprehensive care and support plans in partnership with people using NHS CHC funded services.

The result of poor care and support planning can mean that a person's care needs are not being fully met. In the cases we have seen, and those included here, families have paid for care outside of the CCG arranged care package. Two of the cases included here have resulted in CCGs repaying over £250,000 in redress to families that have paid out or provided care themselves to ensure their relatives received the care they needed.

Although the circumstances of each of the cases we have seen are unique, they all demonstrate the importance of effective and thorough care and support planning. Care and support planning must also be undertaken with the involvement of the person and their families or other representatives, as required by the existing guidance in the National Framework.

Mr S and Ms E's stories both show how failure to produce a care and support plan can create situations where people are forced to pay out large sums of money to make sure their loved ones get the care they need. While the families in these case summaries have been able to find the money to pay for care, others will not be able to. This could have hugely damaging consequences.

Ms P's story shows the importance of robust decision making in care and support planning when reviewing an individual's care needs. This process must be inclusive, evidence based and supported by good communication with the person and their family.

It is imperative that CCGs strive to get care and support planning and commissioning right first time. People must get the care they need and are entitled to at the time they need it, and not be forced to make the financial and emotional sacrifices experienced by many of the people and their families who complain to PHSO.

We make the following recommendations to support the frontline workforce to make quality, evidence-based and person-centred decisions:

Recommendation 1: Supporting the skills and experience of NHS CHC practitioners locally

CCGs should assure themselves that those involved in assessing care needs and developing care and support plans are appropriately skilled and experienced using the CHC Competency Framework. Regular training should be made available to frontline practitioners to ensure best practice is followed. At the least, CCGs should ensure frontline practitioners have undertaken learning from the NHS England and NHS Improvement e-learning tool to increase their knowledge and understanding.

Recommendation 2: Sharing learning nationally

In the short-term, NHS England and NHS Improvement should review the NHS CHC e-learning tool and other learning opportunities to ensure they take account of the learning from the case summaries included here and update them to ensure they provides

effective support to the frontline NHS CHC workforce responsible for care and support planning and commissioning.

Recommendation 3: Putting learning into practice

In the long-term, NHS England and NHS Improvement should consider what additional support and coaching it can provide to care systems, CCGs and NHS CHC frontline staff to ensure they are appropriately supported and skilled in care and support planning and commissioning.

Recommendation 4: Supporting people and providers through the NHS CHC process

CCGs should ensure all parties to an NHS CHC-funded package of care are aware of the principles of NHS CHC funding and arrangements for additional services. CCGs should clearly explain in care and support plans what is included in the care package to meet the assessed needs, and the process that should be followed if any additional services or charges need to be considered.

Failings in reviews of previously unassessed periods of care

Sometimes, a person's care needs can change over a long period of time and it can be difficult to ensure NHS CHC funding begins at the start of when a person becomes eligible. For example, a person may have been self-funding social care, either in a care home or in their own home. Over time, their care needs may change. They may subsequently be assessed as eligible for NHS CHC, but there is a period where their care needs had not been assessed. People can request a review of these periods, called a review of previously unassessed periods of care.

In 2012 and 2013, structural changes were made to the NHS following the Health and Social Care Act (2012).

Primary Care Trusts' (PCTs) responsibilities for NHS CHC passed over to the newly established CCGs. As part of this change, the Department of Health set a series of deadlines for retrospective NHS CHC reviews.[21] These deadlines meant that any claims for previously unassessed period of care relating to the period 1 April 2004 to 31 March 2011 had to be submitted by 30 September 2012. For periods of care between 1 April 2011 and 31 March 2012, they had to be submitted by 31 March 2013.

The Strategic Health Authorities[22] jointly developed guidance[23] to support claims for previously unassessed care in accordance with the deadlines set by the Department of Health. PHSO is still making decisions on cases relating to periods of care covered by the 2012 closedown deadlines because of the length of

[21] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215113/dh_133052.pdf

[22] Strategic Health Authorities were regional bodies which were part of the NHS structure between 2002 and 2013. They were replaced by NHS England.

[23] https://www.sheffieldccg.nhs.uk/Downloads/CHC%20documents/DH%20Guidance.pdf

time it has taken for people to receive a final answer from their CCG, and then to make a complaint and receive a response. This is in part due to the high volumes of requests received and the two-stage review process as set out in legislation.

However, complaints are also coming to PHSO relating to previously unassessed periods of care dating from after 2012, which are not explicitly covered by the guidance.

For example, one family was denied a review of a previously unassessed period of care from 2012- 2014 because the CCG said it had not been specifically told it should review these periods by the Department of Health or NHS England.

The reasons for mistakes when reviewing previously unassessed periods of care are diverse and can be complicated. Included in this report are a range of cases which demonstrate where CCGs have made mistakes.

For example, in two cases included in this report, CCGs have relied on earlier flawed decisions and communications to rule out reviewing periods of care. In one case, a letter explaining a decision was sent only to the person receiving care who lacked capacity to review the decision. In another case, we saw a catalogue of errors in checklists and assessments which meant the decisions made about the person's care were not robust.

In other cases, CCGs have put arbitrary barriers in place to providing appropriate redress for people eligible for NHS CHC. For example, one CCG did not do enough to gather evidence that the family had paid for care, meaning it was unfair in not reimbursing the family.

In some of the cases, we have either recommended a full review of a period of previously unassessed care following an investigation, or the CCG has agreed to undertake such a review following our intervention. Sometimes these reviews have not resulted in any additional eligibility for NHS CHC funding. This is just as important an outcome as a finding of eligibility and financial redress, as it gives certainty to the person or their family. For example, it can help with settling a person's estate – one of the cases included in this report was brought to us by a company acting as an executor.

What the National Framework says

The National Framework says that anyone who may be in need of NHS CHC should be assessed. However, the National Framework does not set out how CCGs should handle a request for a previously unassessed period of care.

> 83. The Standing Rules require a CCG to take reasonable steps to ensure that individuals are assessed for NHS Continuing Healthcare in all cases where it appears that there may be a need for such care.

Figure 2: The National Framework for NHS Continuing Healthcare and NHS-Funded Nursing care

In 2012, the Strategic Health Authorities published additional guidance for CCGs handling requests for assessments of previously unassessed care.[24] This guidance was intended to support local commissioners to handle reviews that were the result of the deadlines imposed by the Department of Health. It applies only to periods of care between 2004 and 2012. It has not been updated since 2012, nor has it been superseded.

This guidance sets out that reviews of previously unassessed periods of care should follow the same process as new referrals, as would have been required at the time of the care. For example, any claims relating

24 https://www.sheffieldccg.nhs.uk/Downloads/CHC%20documents/DH%20Guidance.pdf

to care before the National Framework was introduced in 2007 should follow the local criteria in place at the time. Claims for periods of care after that should be assessed according to the National Framework. Nonetheless, the guidance said that the principles of the National Framework should be regarded for all reviews regardless of the date when the period of care was being assessed.

In particular, this guidance said that the commissioner should collect all care records, GP records, any hospital records, social care records or records from other NHS services and put together a document setting out the person's needs as the starting point for the full assessment. This should then be used by the multi-disciplinary team or panel to complete the Decision Support Tool and determine eligibility.

While this guidance only applies to periods of care between 2004 and 2012, the complaints we have seen include examples where CCGs have been advised by NHS England that they should review previously unassessed periods of care from after the 2012 closedown. The guidance[25] for CCGs on recording data related to NHS CHC also sets out how previously unassessed periods of care from both before and after 2012 should be recorded, recognising that it is "still possible for CCGs to receive requests for 'non-closedown' [previously unassessed periods of care] relating to periods of care after 31 March 2012".

What our casework tells us: failings in reviews of previously unassessed periods of care

Ms U's story

Ms U was diagnosed with Alzheimer's dementia in 2004. In 2008, the Primary Care Trust (PCT) completed a checklist to assess her eligibility for a full assessment for NHS CHC. Following this, the PCT wrote to Ms U to inform her she was not eligible for an NHS CHC assessment.

In 2009, the PCT reassessed Ms U and found she was eligible for NHS CHC.

In 2016, Ms U's family requested a review of her eligibility for NHS CHC for the full period between 2004 and 2009. The CCG refused because a pre-assessment checklist had been completed in 2008 and indicated she would not be eligible. The family disputed this and requested copies of all past checklists, assessments, and correspondence for the period from 2004 to 2009. The CCG provided the checklist which showed Ms U was not eligible for a full NHS CHC assessment.

In 2017, the family requested a full review of the period from 2004 to 2008 stating that this period had not been assessed. The CCG reviewed this period and found Ms U was not eligible for NHS CHC. It also restated that as a checklist had been completed in 2008, it would not review the period from 2008 to 2009.

We found that the 2008 decision that Ms U was not eligible for a full NHS CHC assessment had only been communicated to her and not her family. This was a failing because Ms U did not have capacity to understand and challenge the decision. The National Framework states that in this case, the decision, and reasons for it, should be communicated to a carer or representative. They should also be informed about their right to challenge the decision and details of their rights under the NHS complaints procedure. This did not happen.

We found that the scores on the checklist reflecting Ms U's condition were not supported by information in her medical records. This meant that the decision was not evidence-based or robust.

25 https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2020/06/Funded-Care-Report-Guidance-2020-21-V1.0.pdf

We recommended the CCG review the checklist from 8 July 2008 to determine whether Ms U required a full NHS CHC assessment. The CCG concluded that the checklist was completed incorrectly and carried out a full assessment of Ms U's eligibility.

Mr J's story

Mr J was awarded retrospective NHS CHC funding for a five-month period in 2011, to be paid to his estate. His niece, Ms D, was the executor of his estate and the CCG asked her to provide evidence of payments for Mr J's care. Ms D asked Mr J's nursing home to provide this evidence, which she in turn gave to the CCG.

The CCG decided this evidence was not sufficient, because it did not show proof of the charge for the care, or that the payments were made. The CCG told Ms D it needed bank statements as evidence of the payments. Ms D was unable to source bank statements from Mr J's account.

The CCG's own guidance states that where there are gaps in evidence for reviews of previously unassessed periods of care, the CCG should ask the care home or other relevant organisations for evidence, with the claimant's permission.

For example, the CCG should have asked the local authority if it contributed towards the cost of the claimant's care. It could also ask the claimant's GP to verify the claimant's address during the period in question. As a last resort, guidance states the CCG should reimburse the claimant at the rate of the CCG's predecessor, the Primary Care Trust (PCT).

We found no evidence to show that the CCG attempted to gather evidence from any of these sources, or pay the claimant at the PCT rate, in line with its own guidance.

We recommended that the CCG obtain the necessary evidence of fees, or make a calculation based on precedent, and reimburse Mr J's estate. The CCG subsequently paid Mr J's estate over £6,000

Ms V's story

Ms V was resident in a nursing home from 2008 to her death in 2010. Following her death, the company acting as executor of her estate sought a review of her NHS CHC eligibility for the period from 2008 to 2010.

The CCG wrote to the nursing home in November 2014, June 2015 and October 2015 requesting Ms V's care records. The nursing home did not respond. The CCG closed the case in October2016.

The company acting as executor then obtained the records itself and made them available to the CCG. The CCG refused to review the care as the records had not been provided within a particular timescale.

We found the CCG did not do enough to obtain the records from the nursing home. It did not follow the 2012 guidelines for previously unassessed periods of care, which required it to collect all nursing home records. It also did not follow its own local policy, which set out the timescales and escalation process it should have followed when it did not receive a response from the nursing home.

We recommended the CCG undertake a full review of the care period in question.

Ms W's story

Ms W died in 2015. She had been receiving care for the three years leading up to her death, which had been paid for by her family. Following her death, the CCG reviewed her care needs for the three months prior to her death and found her eligible for NHS CHC funding.

The family then requested a full review of Ms W's care for the three years leading up to her death. The CCG only reviewed an additional three-month period prior to their earlier decision of eligibility, finding that she was not eligible. The CCG used this decision to say that a further assessment of the care from 2012 to 2014 was not needed.

We asked the CCG for an explanation why it had not assessed the full period of care. Our intervention prompted the CCG to work with the NHS England regional team to get clarity on whether to review the whole period. NHS England confirmed that the CCG should review the whole period. The CCG agreed to carry out this review.

Ms K's story

Ms K was a resident in a nursing home from 2012 until her death in 2014. In 2016, her family requested the CCG review her eligibility for NHS CHC.

The CCG declined to review the period. It said it was not currently required to review the period of care and it was awaiting national policy and guidance on how to process requests relating to this period. Ms K's family complained to the CCG about this decision, but the CCG reiterated its decision. It said that there was only guidance for claims for periods of care from 2004 to 2012. The CCG said it had received no policy or guidance from the Department of Health or NHS England on how to process claims for previously unassessed periods of care dating from April 2012 onwards. Ms K's family then brought their complaint to PHSO.

We found that, although specific guidance did not exist, NHS England had told the CCG that it should undertake reviews of previously unassessed periods of care from after April 2012. We found no reason why the CCG should not have reviewed the care. We found that the CCG had denied Ms K's family the opportunity to review Ms K's eligibility for NHS CHC.

We recommended the CCG review the period of care. We also recommended the CCG reverse its decision not to review previously unassessed periods of care dating from after 2012.

Ms R's story

Ms R was in a nursing home for seven years leading up to her death in 2013. Over this period, the CCG's predecessor had either screened or assessed her needs on several occasions. There were also periods of care that had not been assessed.

Ms R's family asked the CCG to undertake a full review of care for the whole seven-year period as they felt the proper processes had not been followed. The CCG decided not to review the period because its records showed that Ms R had been screened and assessed appropriately for the period.

We found that there were errors throughout the screenings and assessments the CCG's predecessor conducted. Some screening checklists were not fully complete. At other times, the reviews did not consider NHS CHC. There was poor communication about decisions, which did not mention the right to appeal decisions. A period of three months, which should have been assessed for NHS CHC, was not assessed. One screening checklist should have prompted a full assessment for eligibility, but this was not carried out.

We concluded that the decision-making process was not robust and Ms R's care needs had not been properly assessed. The CCG should have identified these mistakes. We recommended the CCG undertake this review.

Conclusions and recommendations

The cases we have seen about reviews of previously unassessed periods of care date back many years, in some cases more than a decade. The deadlines set in 2012 resulted in 63,000 requests to review a previously unassessed period of care and we are still seeing complaints reach us now from this period. The two-stage process for review, involving firstly the local CCG and then a review by NHS England, has meant people have waited many years for an answer to whether or not they or a relative were eligible for NHS CHC. Patients and families have been left with significant uncertainty about their financial situation for far too long.

CCGs should aim to be person-focused and seek to ensure people get certainty around assessment and eligibility for previously unassessed periods of care promptly. In many of the cases we have seen, the people who received care that had not been assessed for NHS CHC have died. CCGs must seek to treat them and their families with compassion and respect. They should deliver timely, evidence-based decisions, redress, and certainty.

The guidance for CCGs in reviewing previously unassessed periods of care was published in 2012 to support CCGs and their predecessor organisations. It was developed specifically to support those organisations to process previously unassessed periods of care between 2004 and 2012 in the context of the deadlines set by the then Department of Health.

While some of the cases we have closed recently date back to the periods covered by this guidance, it is now eight years since it was published. However, as seen from the cases included here, particularly Ms K's story, complaints to PHSO cover periods of care that come after the period covered by the guidance. The lack of clarity for previously unassessed periods of care from after April 2012 has caused CCGs to deny people the opportunity for a review.

This lack of guidance covering care since April 2012 risks frontline practice being at odds with the principles of the National Framework, and CCGs being confused about their responsibilities. The complaints we have seen include examples where CCGs have been advised by national bodies to review previously unassessed periods of care after 2012, but national guidance does not make clear whether CCGs are required to do this. The Department of Health and Social Care, and NHS England and NHS Improvement should consider the approach to previously unassessed periods of care from April 2012 onwards and publish guidance for CCGs setting out their obligations.

Recommendation 5: Developing national guidance

The Department of Health and Social Care (DHSC) and NHS England and NHS Improvement should consider the approach to previously unassessed periods of care dating from after 2012 and develop guidance to clarify CCGs' obligations. Guidance should set out explicitly how CCGs should respond to requests to retrospectively assess people's eligibility for NHS CHC-funded care such as Ms W's and Ms K's, whose requests relate to periods of time after the 2012 closedown. This guidance should make clear what CCGs' obligations are and give clear and specific timeframes for CCGs to meet these obligations. If deadlines for requests are imposed, these should be effectively communicated by CCGs to anyone who may have been affected to ensure no one is disadvantaged.

Recommendation 6: Delivering capability in the NHS CHC system

Once this guidance is in place, CCGs should assure themselves, with support from NHS England and NHS Improvement, that they have sufficient capability to successfully meet their obligations as set out in the guidance. Where assessments of previously unassessed periods of care are required by the guidance, CCGs should ensure they can complete timely and quality reviews.

Making change happen

This report is published in extremely challenging times for the NHS as it tackles the COVID-19 pandemic. For CCGs, this has been felt acutely as frontline and administrative NHS CHC staff have been redeployed to support the national effort during these unprecedented times.

However, it is crucial the recommendations and learning set out in this report are taken forward to further improve the NHS CHC system and the service provided to some of the most vulnerable people in society. NHS CHC is there for people with complex care needs. Not getting this right can have life-changing financial, emotional and practical consequences for people and their families.

We hope the learning and recommendations we have set out in this report inspire and support CCGs to get it right first time. The recommendations are practical and achievable, but we recognise the unprecedented pressures on the NHS due to COVID-19 mean that it may take longer than usual for them to be implemented. We ask the Department of Health and Social Care, and NHS England and NHS Improvement to write to the Public Administration and Constitutional Affairs Committee and the Health and Social Care Select Committee in six months with an update on progress in planning and delivering these recommendations.

Annex - About NHS Continuing Healthcare

NHS CHC is care provided to someone who has complex care needs. The care can be provided in someone's own home, a care home or other place outside of a hospital. This care is paid for by the NHS and covers the full cost of the person's care and residential needs.

Eligibility for NHS CHC funding is determined by whether a person has a 'primary health need'. This means that the main aspects of the care they require are focused on addressing health needs. Having a primary health need is not about the reason why an individual requires care or support, nor is it based on their diagnosis; it is about the level and type of their overall actual day-to-day care needs taken in their totality.

Local CCGs are at the frontline of NHS CHC, as they are responsible for assessing people's needs, and arranging and funding care. CCGs do this under the National Framework.[26] The National Framework is underpinned by the Standing Rules regulations[27], which require CCGs to follow it.

The National Framework was first published in 2007 and sets out the process CCGs should follow to determine eligibility for NHS CHC and arrange appropriate care. It provides a checklist[28] for initial screening as well as a detailed decision support tool[29] for NHS CHC practitioners to use when assessing whether someone is eligible for NHS CHC funding.

[26] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/746063/20181001_National_Framework_for_CHC_and_FNC_-_October_2018_Revised.pdf

[27] https://www.legislation.gov.uk/uksi/2012/2996/contents

[28] https://www.gov.uk/government/publications/nhs-continuing-healthcare-checklist

[29] https://www.gov.uk/government/publications/nhs-continuing-healthcare-decision-support-tool

The scale of NHS CHC in England

In 2015-16, NHS CHC cost CCGs £3.6billion, and by 2020-21 was expected to cost £5.2billion.[30] However, savings have been made in the administration of NHS CHC and growth has not been as fast as previously anticipated. In 2018-19, NHS CHC cost approximately £3.7billion.[31] Although savings have been made and growth in spending is slower than had been expected, it still represents approximately 4% of CCG spending. There is no cap on NHS CHC funding, which means all those eligible should receive the funding they need.

According to NHS England and NHS Improvement, these savings have been made without any changes to eligibility.[32] In 2015-16, almost 160,000 people were eligible for NHS CHC funding[33] and in 2019-20, this figure was 166,000.[34] The proportion of those referred to CCGs for consideration who are eligible for NHS CHC funding has remained fairly constant: in 2015-16, 18% of those referred were eligible and in 2019-20, 19% were eligible.

NHS CHC is split between 'standard' CHC for people with a primary health need and 'fast track' for people with a rapidly deteriorating illness that may be entering a terminal phase. The majority (87.5%) of people who are eligible for NHS CHC funding are on the fast track. There are different processes in place for each type. People referred for standard NHS CHC go through a more detailed assessment process. The fast track process is more streamlined allowing a suitable clinician to determine a person's eligibility.

[30] https://www.nao.org.uk/wp-content/uploads/2017/07/Investigation-into-NHS-continuing-healthcare-funding-1.pdf

[31] https://www.kingsfund.org.uk/publications/social-care-360/connections

[32] https://www.england.nhs.uk/wp-content/uploads/2019/03/04_MiCIE_PB_28_03_2019-Finance-and-Performance.pdf

[33] https://www.nao.org.uk/wp-content/uploads/2017/07/Investigation-into-NHS-continuing-healthcare-funding-1.pdf

[34] https://www.england.nhs.uk/statistics/statistical-work-areas/nhs-chc-fnc/

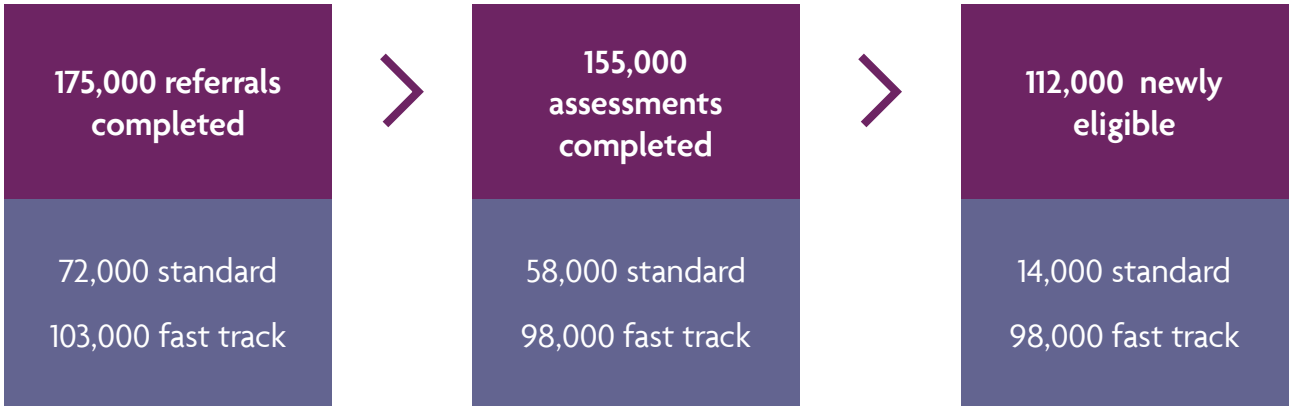

Figure 3: NHS CHC eligibility 2019-20

In 2019-20, there were 3,327 reviews of eligibility completed by CCGs, 4.6% of the total referrals (though these are not directly related as the reviews may be for decisions made in previous years). Of these, 588 (18%) resulted in eligibility.

Who does what

The Department of Health and Social Care produces the National Framework for Continuing Healthcare and NHS Funded Nursing Care. It last updated the National Framework in 2018.

CCGs are at the frontline of NHS CHC in England. CCGs are responsible for screening referrals and assessing eligibility for NHS CHC funding. For standard NHS CHC funding, this is a two-stage process:

- on referral, CCGs will screen using the NHS continuing healthcare checklist[35]
- CCGs will then carry out a full assessment to decide on eligibility, using the NHS continuing healthcare decision support tool.[36] This requires the input of a Multidisciplinary Team (MDT).

Once a person's eligibility for NHS CHC funding is confirmed, the CCG is then responsible for care planning, service commissioning and case management. This includes regular reviews of care needs.

CCGs are also responsible for undertaking reviews of eligibility and must have a local resolution process set out. This includes requests to review previously unassessed periods of care. If a case cannot be resolved locally, the individual can seek an independent review.

NHS England and NHS Improvement is responsible for undertaking the independent review of eligibility decisions. This process includes taking the case to an Independent Review Panel.

If the person is dissatisfied with the decision of the Independent Review Panel, they can follow the NHS Complaints Procedure and bring a complaint to the Parliamentary and Health Service Ombudsman.

[35] https://www.gov.uk/government/publications/nhs-continuing-healthcare-checklist

[36] https://www.gov.uk/government/publications/nhs-continuing-healthcare-decision-support-tool

The review process is free for people who need to use it. Nonetheless, people sometimes need support. Every area in England has an independent NHS complaints advocacy service funded by the local authority[37]. They can help people make a complaint about the NHS. There are a number of providers, and local Healthwatch[38] organisations can provide details.

Additionally, NHS England and NHS Improvement has funded Beacon to provide a free advice service, allowing up to 90 minutes of information and support to help people trying to navigate the NHS CHC system.[39]

Some firms, such as Beacon, operate services supporting people to pursue claims for NHS CHC funding. This can be on an hourly rate or a no-win-no-fee basis. There is no requirement for people to use a paid-for service to seek an NHS CHC review.

PHSO's previous work and the evolution of NHS CHC since 1994

In 1994, the then Ombudsman published a report[40] of an investigation about a health authority's failure to provide long term care for a man who had brain damage. We found that the health authority had a policy not to provide care for people with a neurological condition.

Following this, in 1996 the then Ombudsman published a report[41] containing five similar cases. These cases highlighted the impact of poor local arrangements for people requiring long term care because of a primary health need, where national guidance had not been followed.

In between these two reports, the Department of Health put in place the first national guidance for local health authorities. This guidance did not provide a national set of eligibility criteria, but did require local written policies and criteria, and listed the type of needs that should be covered.

In 1999, a legal case known as the Coughlan Judgement put in law the principle that if a person's need was primarily health based, responsibility for that person's care lied with the NHS. To reflect this, the Department of Health updated the national guidance both immediately after the Coughlan Judgement and again in 2001, to take account of its findings.

In 2003, we published the first of three linked reports[42] on NHS CHC, as a result of an increase in the numbers of complaints we were receiving. This report looked at cases dating between 1997 and 2001. We found that national guidance had not provided the secure foundation needed for a fair and transparent system. The guidance that did exist had been misinterpreted and misapplied.

In the 2003 report, we recommended the Department of Health and health authorities review the criteria used between 1996 and 2002 and make efforts to right any financial wrongs. We also recommended that the Department of Health review the national guidance to make it clearer where the NHS must fund care.

[37] https://www.citizensadvice.org.uk/health/nhs-and-social-care-complaints/complaining-about-the-nhs/who-you-can-go-to-when-you-have-a-problem-with-the-nhs/organisations-that-can-help-you-make-a-complaint-about-health-services/

[38] https://www.healthwatch.co.uk/

[39] https://www.beaconchc.co.uk/how-we-can-help/free-information-and-advice-on-nhs-continuing-healthcare/

[40] https://www.gov.uk/government/publications/report-of-the-health-service-commissioner-failure-to-provide-long-term-nhs-care-for-a-brain-damaged-patient

[41] https://www.gov.uk/government/publications/investigations-of-complaints-about-long-term-health-care

[42] https://www.gov.uk/government/publications/health-service-ombudsman-nhs-funding-for-long-term-care-2nd-report-session-2002-to-2003

Following the 2003 report, the Ombudsman received 4,000 complaints and the Department of Health set aside £180 million to fund retrospective claims.[43]

In 2004, the then Ombudsman published a follow up report[44], which looked at how local NHS organisations had processed the retrospective reviews brought about by her 2003 report. This reiterated the need for clear national guidance and support for local NHS organisations to apply eligibility criteria. In response, the Department of Health announced it would be developing a nationally consistent approach.

In 2006 another legal case, known as the Grogan Judgement, highlighted further criticisms of the national guidance and local variance in eligibility criteria.

In 2007, the Department of Health published the first version of the National Framework, introducing national eligibility criteria, processes, and tools to support decision making. This was followed in 2009 by a revised framework establishing a fast track for people with a rapidly deteriorating condition.

Also in 2007, we published a further report,[45] looking at how the Department of Health had established redress for those found eligible as a result of our 2003 report. We found the Department had made a mistake in how it decided to calculate the amount people were entitled to, taking no account of the actual costs to people and the impact of the previous system.

The Department of Health published a revised National Framework in 2012 to take account of structural changes in the NHS, notably the introduction of Clinical Commissioning Groups in place of the previous Primary Care Trusts. As part of this, in 2012 the Department put in place a series of deadlines for people to request a review of a previously unassessed period of care covering the period 1 April 2004 to 31 March 2012. This was intended to give CCGs a clear slate for NHS CHC assessments and ensure there was a limited backlog of claims.

NHS England and NHS Improvement is currently undertaking the Continuing Healthcare Strategic Improvement Programme.[46] This will run until 2021 and aims to:

- reduce the variation in patient and carer experience of NHS CHC assessments, eligibility and appeals
- ensure that assessments occur at the right time and place, with fewer assessments taking place in hospitals
- work with CCGs across the country to identify best practice that can be adopted by other CCGs
- set national standards of practice and outcome expectations.
- make the best use of resources – offering better value for patients, the population and the taxpayer
- strengthen the alignment between other NHS England and NHS Improvement work programmes which have a CHC component, such as Personalisation and Choice.

[43] https://publications.parliament.uk/pa/cm200708/cmhansrd/cm080116/text/80116w0034.htm

[44] https://www.gov.uk/government/publications/health-service-ombudsman-first-report-session-2004-to-2005

[45] https://www.gov.uk/government/publications/retrospective-continuing-care-funding-and-redress-3rd-report-session-2006-2007

[46] https://www.england.nhs.uk/healthcare/nhs-chc-strategic-improvement-programme/

The Continuing Healthcare Strategic Improvement Programme has led to the development of the NHS CHC e-learning tool[47] and the CHC Competency Framework for frontline staff in CCGs. Apprenticeships schemes and a level 7 Open University qualification are also in development. The Continuing Healthcare Strategic Improvement Programme seeks to address the issues raised in recent years by organisations such as the National Audit Office and the Continuing Healthcare Alliance (see below).

In 2018, the Department of Health and Social Care published a revised National Framework. This did not change any of the eligibility criteria but was designed to provide greater clarity around the assessment process, the role of CCGs and local authorities, and reflect some legislative changes. Specifically, the changes included:

- setting out that the majority of NHS CHC assessments should take place outside of acute hospital settings
- providing additional advice for staff on when individuals do and do not need to be screened for NHS CHC in order to reduce unnecessary assessment processes and provide greater clarity on this
- clarifying that the main purpose of three and 12-month reviews is to review the appropriateness of the care package, rather than reassess eligibility. This should reduce unnecessary re-assessments
- introducing new principles for CCGs regarding the local resolution process for situations where individuals request a review of an eligibility decision. The aim is to resolve such situations earlier and more consistently
- providing clearer guidance, including dedicated sections, on: the roles of CCGs and local authorities, NHS-funded Nursing Care, inter-agency disputes, well-managed needs, and the Fast Track Pathway Tool.

During the COVID-19 crisis of spring and summer 2020, all new NHS CHC assessments were paused to allow CCGs the flexibility and extra capacity to manage the additional pressures on the NHS. This meant the NHS funded all care for people who would otherwise have been referred for an NHS CHC assessment, and assessments were deferred. Assessments were restarted on 1 September, both for new referrals and for those deferred. Additional guidance was introduced to support CCGs to carry out these assessments.[48]

NHS England and NHS Improvement has also developed a programme of work to support CCGs with the deferred assessments, including supporting the workforce, and securing additional resources for CCGs to increase capacity as well as providing additional e-learning material.

[47] https://www.england.nhs.uk/healthcare/nhs-ch/

[48] https://www.gov.uk/government/publications/reintroduction-of-nhs-continuing-healthcare/reintroduction-of-nhs-continuing-healthcare-nhs-chc-guidance

1994 – PHSO report Failure to Provide Long Term NHS Care for a Brain-Damaged Patient

1996 – PHSO report Investigations of Complaints about Long Term Health Care

1999 – The Coughlan judgement

2003 – PHSO report NHS Funding for Long Term Care

2004 - PHSO follow-up report NHS Funding for Long Term Care

2006 – The Grogan judgement

2007 – PHSO report Retrospective Continuing Care Funding and Redress

2007 – National Framework for NHS Continuing Healthcare and NHS-Funded Nursing Care

2009 – Revised National Framework for NHS Continuing Healthcare and NHS-Funded Nursing Care published, establishing the fast track for people with a rapidly deteriorating condition

2012 – Revised National Framework for NHS Continuing Healthcare and NHS-Funded Nursing Care published

2012-2013 Deadlines imposed for reviews of previously unassessed periods of care between 2004 and 2012

2016 – CHC Alliance report, Continuing to Care? Is NHS Continuing Healthcare Supporting the People Who Need it in England?

2016 – NAO Investigation into NHS Continuing Healthcare Funding

2017-2018 – Equalities and Human Rights Commission considered legal action against CCGs which had blanket caps on funding

2018 – Public Accounts Committee report on Continuing Healthcare

2017-2021 – NHS CHC Strategic Improvement Programme

2018 – Revised National Framework for NHS Continuing Healthcare and NHS Funded Nursing Care published

2020 – COVID-19 response paused new NHS CHC assessments between March and September

What others have said

Several other organisations have looked at issues with NHS CHC in recent years.

National Audit Office and Public Accounts Committee

The National Audit Office (NAO) is the UK's independent public spending watchdog and supports Parliament in holding the Government to account. It helps improve public services through high-quality audits. NAO reports into Parliament's Public Accounts Committee (PAC), which scrutinises public spending and holds the Government to account.

In 2017, NAO published its investigation into NHS continuing healthcare funding.[49] NAO found that the assessment process raises people's expectations that they will receive funding. They noted that only 18% of initial screenings result in a person being assessed as eligible.

NAO noted that NHS CHC was a significant cost pressure on CCGs' spending, but that there is local variation in the number and proportion of people assessed as eligible. It said this variation could not be explained by population differences, meaning that it was likely there were differences in how CCGs interpreted and applied the National Framework and eligibility criteria.

NAO also noted there were limited assurance processes to ensure consistency in decision making at CCGs, and that there was a shortage of data on NHS CHC.

Following the NAO report, PAC held an inquiry and published its report in 2018.[50] PAC largely echoed NAO's findings. It found that people waited too long to find out if they were eligible and that some people did not receive the care they were entitled to because of a complex system. PAC also found too much local variation in the interpretation of the National Framework and its assessment tools.

Continuing Healthcare Alliance

The Continuing Healthcare Alliance is a group of 17 charities and organisations that share a belief that NHS CHC needs to improve. Continuing Healthcare Alliance members include Parkinson's UK, Age UK, Marie Curie, Beacon, Carers Trust, Patients Association and other charities and organisations that have an interest in NHS CHC.

In 2016, the Continuing Healthcare Alliance published Continuing to care? Is NHS continuing healthcare supporting the people who need it in England?.[51] In this report, the Alliance made a series of recommendations for national and local organisations to ensure improvement in NHS CHC:

- ensure multidisciplinary teams are composed of professionals who are experienced when making decisions around NHS CHC, with knowledge of the person, their condition(s), needs and aspirations
- design and deliver a mandatory programme of training for professionals who organise and assess people for NHS CHC to ensure they understand the eligibility criteria and how to use the current decision tools
- rewrite the checklist and Decision Support Tool so they more effectively measure individuals' healthcare needs against the lawful limit of care that the local authority can provide

[49] https://www.nao.org.uk/wp-content/uploads/2017/07/Investigation-into-NHS-continuing-healthcare-funding-1.pdf

[50] https://publications.parliament.uk/pa/cm201719/cmselect/cmpubacc/455/455.pdf

[51] https://www.parkinsons.org.uk/sites/default/files/2018-04/CS2332%20Continuing%20to%20Care_Report_Hyperlinks.pdf

- introduce an option for professionals to select if they agree someone should not be reassessed for eligibility of NHS CHC. For people marked down as permanently eligible, reviews should only look at changing needs, for example, where someone may need increased support
- prevent people with long-term, serious health conditions being forced into residential care, or living at home with unsafe levels of care, by ensuring packages of care are needs-driven and not purely financially motivated
- publish data on how many people apply for NHS CHC – whether they are successful or not – as well as the number of people who proceed past the checklist stage to the full assessment.

Equalities and Human Rights Commission

The Equalities and Human Rights Commission (EHRC) is Great Britain's national equality body. It works to safeguard and enforce the laws that protect people's rights to fairness, dignity and respect.

In 2017, EHRC looked at taking legal enforcement action against CCGs having become concerned about CCGs having blanket policies with arbitrary caps on funding.[52] EHRC said that such policies failed to consider individual needs, such as living location and family life, and were a breach of the Human Rights Act and the Public Sector Equality Duty.

EHRC wrote to 43 CCGs asking for more details about their approach, before initiating judicial review proceedings against 13 CCGs. These 13 CCGs subsequently reviewed their policies.[53]

[52] https://www.equalityhumanrights.com/en/our-work/news/nhs-facing-court-action-over-unlawful-policies

[53] https://www.equalityhumanrights.com/en/our-work/news/nhs-u-turns-discriminatory-policies

Glossary

Care and support plan

The care and support planning process is central to the commissioning and provision of care to meet an individual's needs. Responsibility for care planning lies with the CCG. A care and support plan should ensure a person's care package meets all their assessed needs.

CCG - NHS Clinical Commissioning Groups

NHS Clinical Commissioning Groups were set up by the Health and Social Care Act 2012 and commission most of the hospital and community NHS services in the local areas for which they are responsible. CCGs lead NHS CHC in their local area, making decisions on eligibility and leading the care and support planning process and commissioning care services.

CHC Alliance - Continuing Healthcare Alliance

CHC Alliance is a group of 17 charities and organisations and campaigns for change and improvement in NHS CHC

CHC Checklist

The Checklist is the NHS Continuing Healthcare screening tool which can be used in a variety of settings to help practitioners identify individuals who may need a full assessment of eligibility for NHS Continuing Healthcare.

CHC DST - CHC Decision Support Tool

The DST is a national tool which has been developed to support practitioners in the application of the National Framework. The tool is a way of bringing together information from the assessment of needs and applying evidence in a single practical format to facilitate consistent evidence-based recommendations and decision making regarding eligibility for NHS Continuing Healthcare. All staff who use the DST should be familiar with the principles of the National Framework and have received appropriate training.

DHSC - Department of Health and Social Care

The Department of Health and Social Care is the Government department which oversees the health and social care system in England. It is responsible for development of the National Framework and its associated tools.

EHRC - Equalities and Human Rights Commission

The Equality and Human Rights Commission is Great Britain's national equality body. It safeguards and enforces the laws that protect people's rights to fairness, dignity and respect.

HSCC - Health and Social Care Committee

The Health and Social Care Committee it the Parliamentary committee with responsibility to scrutinise the work of the Department of Health and Social Care and its associated public bodies. It examines Government policy, spending and administration on behalf of the electorate and the House of Commons.

MDT - Multi-Disciplinary Team

An MDT is a team of at least two professionals, usually from both the health and the social care disciplines. The core purpose of the MDT is to make a recommendation on eligibility for NHS CHC drawing on the multidisciplinary assessment of needs and following the processes set out in this National Framework.

NAO - National Audit Office

The National Audit Office (NAO) is the UK's independent public spending watchdog and supports Parliament in holding government to account. It helps improve public services through high-quality audits. NAO reports into Parliament's Public Accounts Committee (PAC).

National Framework - The National Framework for Continuing Healthcare and NHS-Funded Nursing Care

The National Framework sets out the principles and processes of NHS Continuing Healthcare and NHS-funded Nursing Care. At the heart of the National Framework is the process for determining whether an individual is eligible for NHS Continuing Healthcare or NHS-funded Nursing Care.

NHS CHC - NHS Continuing Healthcare

NHS CHC is care provided to someone who has complex care needs. The care can be provided in someone's own home, a care home or other place outside of a hospital. This care is paid for by the NHS and covers the full cost of the person's care and residential needs.

NHS England and NHS Improvement

NHS England and NHS Improvement leads the NHS in England. It was set up under the Health and Social Care Act 2012. Since April 2019 it has operated as a single organisation.

PAC - Public Accounts Committee

PAC is the Parliamentary committee which examines the value for money of Government projects, programmes and service delivery. Drawing on the work of the National Audit Office the Committee holds government officials to account for the economy, efficiency and effectiveness of public spending.

PACAC - Public Administration and Contitutional Affairs Committee

PACAC is appointed by the House of Commons to examine constitutional issues, the quality and standards of administration provided by Civil Service departments, and the reports of the Parliamentary and Health Service Ombudsman (PHSO).

PCT - Primary Care Trust

PCTs were the statutory NHS organisations responsible for commissioning most health services and for improving public health. They were replaced by CCGs by the Health and Social Care Act 2012. Prior to this, PCTs played the same role in NHS CHC as CCGs have since.

Primary health need

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

PUPoC - Previously Unassessed Period of Care

A PUPoC is a historic period of care for an individual whose eligibility for NHS CHC had not been asessed at the time.

Standing Rules - The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012

The Standing Rules are the legal framework for NHS England and NHS Improvement, and CCGs. The Standing Rules set out the roles and responsibilities for NHS England and NHS Improvement and CCGs in relation to NHS CHC and underpin the National Framework.

Strategic Health Authorities

Strategic Health Authorities were regional bodies which were part of the NHS structure between 2002 and 2013. They were replaced by NHS England.

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