



Continuing to care?

Is NHS continuing healthcare supporting the people who need it in England?

Written by Parkinson's UK in association with the Continuing Healthcare Alliance

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Introduction

When you have serious health problems, getting the professional care you, or someone close to you, need shouldn't be a battle. But all too often it is.

NHS continuing healthcare – also known as NHS continuing care or NHS CHC – is free healthcare provided outside of hospital that is arranged and funded by the NHS. It may include paying for care costs typically funded by a local authority under the banner of social care, such as fees for a care home, but where these arise due to a specific health need. When delivered effectively, it can enable people to go on living as full a life as possible. It can also have the benefit of reducing anxiety and minimising pressure on family and friends.

In 2013 the All Party Parliamentary Group (APPG) on Parkinson's conducted an inquiry analysing the state of NHS CHC in England and produced the *Failing to care* report¹. They heard evidence from people affected, professionals in the system, and patient organisations.

After the inquiry, many of the organisations who gave evidence joined together to form the Continuing Healthcare Alliance². The aim of the alliance is to improve NHS CHC for all who rely on it, now and in the future.

Three years since that inquiry, although some improvements have been made, the alliance is extremely concerned that NHS CHC remains inaccessible for many who should qualify for help.

Numerous avenues of support for people with serious conditions are being withdrawn. Social care support is being cut, access to some welfare benefits has been restricted, while other sources of support such as the Independent Living Fund have been scrapped entirely. These cuts make NHS CHC provision even more important.

We will note where positive progress has been made and go on to outline the current challenges

In this report we evaluate each of the following areas, which represent recurring issues for people involved in NHS CHC:

- **In the dark:** the provision of information and advice.
- **Leave it to the experts:** how professionals conduct the assessments.
- **Dysfunctional decisions:** how the Decision Support Tool is used.
- **Why are we waiting?** The delays experienced by people applying.
- **Righting the wrongs:** the appeals process.
- **Who cares and how much?** The provision of care.
- **Say that again:** the impact of regular reassessments.
- **Never the same:** the lack of consistency and consequences.
- **Filling in the blanks:** improving the data that is gathered.

and the potential solutions that would improve the system for the people who need it.

If NHS CHC fails, the alliance believes many people will have no choice about where they live and how their care is delivered. For more than 50 years, the priority has been to support people to live as full a life as possible, independently, in the community. The current trend in health and disability policy is deeply worrying, and some of the evidence we have received suggests this reversal in attitude is already underway.

¹ The All Party Parliamentary Group on Parkinson's (2013) *Failing to care: NHS continuing care in England*. Available at parkinsons.org.uk/sites/default/files/failingtocare_appgfullreport.pdf

² Details of members of the Continuing Healthcare Alliance (formerly known as the Failing to Care Coalition) are stipulated on the back page.

Executive summary

Key problems

The Continuing Healthcare Alliance believes that NHS continuing healthcare (NHS CHC) is failing people across England. The current system attempts to artificially divide the care and support that sick and disabled people need into 'health' care and 'social' care. For example, eating and drinking is considered a social care need while nutrition is a healthcare need. As a result the dividing line between a healthcare need and a social care need is fundamentally blurred. If someone is unable to eat and drink for a sustained period, they wouldn't live for long unless they received medical intervention. Due to flawed processes, many people who should be found eligible are being denied this much-needed support.

Alongside this, those who *are* granted NHS CHC funding are often given inadequate care packages that don't meet their needs.

To provide an accurate picture of how the system works, we've gathered evidence from across England. As well as speaking to people individually, we created two surveys: one for individuals who had applied for NHS CHC, the second for professionals who work on NHS CHC. We also conducted a Freedom of Information (FOI) request that was sent to every Clinical Commissioning Group (CCG) in England³.

Vision for the future

We strongly recommend that NHS England and the Department of Health consider how CHC will operate in the NHS after the implementation of the *Five Year Forward View*, and prepare to make any changes necessary. Patients should be closely consulted during this process to ensure the system operates effectively, and does not continue to be blighted by the failings identified in this report.

The Continuing Healthcare Alliance wishes to support NHS England and the Department of Health with this important task.

Our findings confirm that the system is letting people down:

- **40%** of professionals who completed our survey told us that their experience of decision making in a multidisciplinary team (MDT) can be very mixed. In some assessments opinions are weighted equally, while in others they are not.
- **66%** of survey respondents felt the professionals in the assessment did not possess any in-depth knowledge – or knew very little – about the condition the person being assessed was living with.
- **80%** of professionals surveyed said the Decision Support Tool (DST) was not fit for purpose, or there was room for improvement in some areas.
- Those with well-managed needs are often assessed as being ineligible despite having needs that qualify. Denial or withdrawal of care could result in making their needs worse.
- **42%** of survey respondents who had applied for NHS CHC told us they waited more than 28 days (the deadline set by the National Framework) to receive their final decision regarding eligibility.
- **35%** of survey respondents told us they had been told by the multidisciplinary team that eligibility would be recommended, only to have that decision rejected by the review panel.
- Some CCGs are introducing policies that force people into care homes if the cost of their care is more than a residential care package, irrespective of whether this approach meets their assessed needs.
- When less funding is received patients can be transferred to another care company, resulting in the loss of professional carers that the person and their family know and trust.
- **44%** of people surveyed had gone through at least one reassessment after being awarded NHS CHC.

³ See appendices 2-4 for more information on these surveys and the FOI.

Susan's experience

“ I met my husband, Bob, while at university. After getting his PhD in applied sciences, he became an engineer and went to work for the Ministry of Defence. He worked through the Gulf War, commissioning special equipment for desert conditions. He got the Queen's Commendation. In his early sixties, Bob was diagnosed with an aggressive form of Parkinson's. Within six years he went from being independent to needing a wheelchair, hallucinating, having short-term memory loss, being awake all night and having bowel collapses. I was caring for Bob alone until our Parkinson's nurse suggested we apply for NHS CHC. I had never heard of it so didn't know where to start. She helped me fill in the forms, but I didn't hear anything for four months. When I phoned, the CCG always said they were waiting for more information, but didn't say what. I was shoved from pillar to post. It didn't feel like anyone knew what was going on.

Bob had to move into a nursing home, and passed away aged 70. The day after his death the CHC assessor knocked on my door to conduct his assessment. I explained the situation and she said she'd conduct a retrospective assessment. Seven months later, I received a 64 page document. It came with a covering letter asking me to read through the information and provide comment. I didn't really understand what I was reading, but having to focus on details of Bob's condition was painful and I got very weepy. When I finally got to the end, on the final page it said their decision had already been made, and they were rejecting our application. I couldn't believe it! Surely they should have told me that upfront before I started? The whole process was dreadful. I'm an educated and capable person but I was exhausted and really angry. They seemed to forget they were dealing with real people.



Key recommendations

For NHS CHC to improve, the Department of Health, NHS England, CCGs and local authorities should initiate the following changes:

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



In the dark: the provision of information and advice

People enter the health and social care system when they are at their most vulnerable. With NHS CHC marking the boundary between healthcare and social care, all too often people slip into that void where no one gives them the advice they need. Whether applying for themselves while living with a serious health condition(s), or applying for someone close to them, without good support and information the experience can be a distressing one. Since its introduction, the application and assessment process for NHS CHC has been incredibly complex. Many people told us they had to become overnight 'experts' in a daunting and complicated system.

Positive progress

- NHS England acknowledged there was a need for independent information. To tackle this they funded an information and advice service through a social enterprise specialising in supporting people going through the NHS CHC process, called Beacon. The NHS pays for people to have 90 minutes of free advice.
- In April 2015 the Care Act came into force. It places an obligation on local authorities to provide information and advocacy to individuals. However, it is not clear how much this is happening in practice⁴.

⁴ There is some concerning evidence about Local Authority short term and inadequate funding arrangements for independent advocacy under the Care Act – <http://www.seap.org.uk/getfile/6102>

Current challenges

- **60%** of people in our survey said they did not know about the existence of NHS CHC until very late on in their journey through the health and social care system. When they did find out, it was usually by chance, or being told to apply by a friend.
- Signposting to NHS CHC should come from health and social care professionals but worryingly in our survey only **3%** of respondents told us they found out about NHS CHC from their GP. **5%** were told by their clinician, **15%** were informed by a hospital doctor or nurse, and **11%** found out through their social worker.
- The system is still complicated, confusing and intimidating for those who need NHS CHC. More than half (**54%**) of survey respondents said they were not provided with enough information or advocacy. And it's not just people applying who believe the process is difficult to navigate; **39%** of professional survey respondents said they found the NHS CHC assessment process complicated, and more than three quarters (**78%**) believed the system is difficult or very difficult for patients and their families to navigate.
- **65%** of survey respondents told us they did not feel well informed throughout the process, with **39%** of people saying they did not know what criteria the assessment would measure.

What needs to happen?

- NHS England, CCGs and local authorities need to ensure that there is a clear process for health and social care professionals to proactively signpost individuals to NHS CHC, as well as promoting experienced, independent advocacy and support at every stage.
- NHS England must provide information about the system publicly – including the checklist, Decision Support Tool criteria and details on fast track assessments – through their communication channels and partners.

Jane's experience

“ In October 2015 my mum was diagnosed with motor neurone disease (MND). She was only 72. As a family we were in complete shock. Our dad, who had colon cancer, became mum's main carer. Mum deteriorated very quickly. In January dad died, leaving mum grieving for her husband of over 50 years, and with no full time care. We organised a mix of paid for care alongside friends and family.

She collapsed in February and had a feeding tube fitted directly to her stomach, as she could no longer swallow solid food. We knew it was unsafe to send her home, so she went to a hospice while we waited for a room in a care home. While in the hospice, mum asked the doctor how long she had to live. She was told, 'no more than six months', and the MND medical consultant agreed.

We had a brilliant occupational therapist (OT) who told us about NHS CHC. We'd never heard of it as it's not advertised anywhere obvious. At that time she felt mum wouldn't be eligible for it, but said it might be a good idea to apply for an assessment anyway to get mum into the system. Mum couldn't walk, could hardly move her arms or use her hands, struggled to swallow, and was functionally incontinent. So I found it surprising she didn't think mum would qualify.

My sister contacted the CCG to start the process. We were advised that mum would be assessed a couple of weeks later. No one told us that this wasn't the full assessment, but only a checklist to see if mum would go on to the next stage. I don't know why this was necessary when two independent doctors agreed mum had less than six months to live due to a hugely debilitating



terminal illness. The assessor told us that if mum qualified for a full assessment we'd have to wait at least six weeks.

After doing a bit of research ourselves, we became aware of fast tracking. The CCG told us that this was up to the care home, or mum's GP. We contacted the GP, but he felt it wasn't for him to do. My sister did further research online and sent the GP a link to the documents for fast tracking, with information on what he needed to do. The GP continued to say it wasn't his role. I contacted the MND medical consultant to ask if he could help with this. He replied saying it was a task for the GP or the nursing home. The whole system needs to be reviewed and simplified. It needs to be clear who is responsible for each stage of the process. There should be simple information for patients and carers and CCGs need to have teams in place who provide help.

Mum died in May still waiting for her full assessment. To say I feel let down is a complete understatement. On one hand the NHS implies that they help people with medical conditions that require significant healthcare, and yet the process is so protracted that I'm not sure who actually gets this support. There needs to be more transparency and greater clarity on what should be funded. My mum deserved much better than this.



Leave it to the experts: how professionals conduct the assessments

The first step in the process should involve a qualified health or social care professional using a checklist to evaluate whether the person in need of care qualifies for a full assessment. The full assessment should be co-ordinated by the local CCG or the local authority within defined timescales. A team of professionals join together to conduct the full assessment. This group is called a multidisciplinary team (MDT) and should involve professionals from across health and social care who are familiar with the individual's needs.

Gillian's experience

“ Mum has had Parkinson's for a long time but was coping well until my dad passed away. After his death, she started going downhill. My brother and I stepped in to support her, but eventually her needs got too great and we had to acknowledge she needed round-the-clock care.



I found out about NHS CHC by accident. When it came to the assessment I was nervous they wouldn't understand mum's condition, and what it meant for her day to day. The team was made up of a group of professionals, including a Parkinson's nurse. And to my surprise, the nurse assessor who co-ordinated the multidisciplinary team had just done a course on Parkinson's herself, so she had a really good grasp of the issues. As a family we felt really involved in the assessment. It seemed to me that the MDT all worked together to make their decision, they also wrote a lot of notes. We were lucky, mum was awarded NHS CHC, but I think there is a real risk the wrong conclusion would have been drawn if mum hadn't been assessed by people who were expert in her condition.

Positive progress

- The National Framework was introduced to ensure NHS CHC is implemented in the same way across the country. If every CCG, Commissioning Support Unit (CSU) and local authority followed this guidance CHC provision would more often be implemented to a satisfactory standard. The recommendations include:
 - Defining an MDT as a team of at least two professionals from either the health or social care professions, who have an up-to-date knowledge and understanding of the individual's needs, potential and aspirations.
 - Advising that friends or family who care for the person applying should be included in the assessment process. Our survey results show **44%** of respondents felt fully involved.
 - Stipulating that health and social care professionals with condition-specific expertise are involved when the person being assessed has a diagnosed condition. For example, an assessment of someone with Parkinson's could include a Parkinson's nurse or a neurological nurse. If this isn't possible, every effort should be made to source specialist advice in advance, and this should be considered during the assessment.
- NHS England has developed e-learning training modules for professionals working in the NHS CHC system.
- In some areas of the country CHC teams sit in the local authority, while others are part of the CCG or CSU. When they work well, the nurse assessor works with the family, alongside health and care professionals, to co-ordinate a team of skilled experts to conduct an assessment. They also source evidence from specialists, taking into account the family's views and keeping them updated on the outcome.

Current challenges

- Despite the National Framework being in place, some local decision makers appear to regard it as guidance, choosing which bits they intend to follow.
- Worryingly, **32%** of survey respondents who had applied for NHS CHC told us the assessment was not conducted by an MDT.
- All of the MDT members involved in the assessment should have their opinions valued equally. However, **10%** of professionals who completed our survey told us that opinions were not weighed equally during an MDT. An additional **40%** said they had mixed experiences, where in some assessments opinions are weighed equally and in others they are not. **29%** of people applying for NHS CHC who completed our survey told us that one member of the MDT had their opinion valued more highly than other members.
- The decision on whether someone is eligible for NHS CHC often depends on the quality of evidence. We know this varies greatly, with some assessments resulting in two lines of evidence, while others produce several pages.
- Despite national guidance stating that condition specialists should be included, **66%** of survey respondents felt the professionals in the assessment did not possess any in-depth knowledge – or knew very little – about the condition of the person being assessed.
- We know some assessments take place where members of the MDT have never met the individual or family before.
- The role of the co-ordinating assessor, also known as the nurse assessor, is to co-ordinate the MDT and be impartial. They should not dominate discussions, and their opinion should not be afforded greater weighting than anyone else. However the alliance is aware of instances where this happens.



Emma's experience

“ I'm a neurological conditions clinical nurse specialist. I work with people who live with conditions like multiple system atrophy (MSA), MND, progressive supranuclear palsy (PSP) and Huntington's.

We have an NHS CHC co-ordination team based within my local CCG and they are fantastic. It's very clear who to contact to start the assessment process. If I think someone is eligible, I'll complete the checklist myself. This gets sent to the CHC team which is staffed by nurse assessors. The nurse assessors liaise with the individual and organise an assessment as quickly as possible. They have a can-do attitude and are very responsive. I let them know if I need to be part of the MDT, and they contact a cluster of other relevant professionals, while also ensuring the patient and their representatives are involved.

Sometimes a decision is made the same day, which means the families know there and then whether they qualify. When NHS CHC is awarded, the nurse assessors help co-ordinate the care package. My patients often have very complicated conditions which can mean they need to access hugely costly and complex care packages. If this is what is required, it is put in place. Often the agencies used are more expensive and specialist than the ones the council are able to employ. We are always driven by the need of the patient, rather than being led by the price of the care needed.

Chloe's experience

“ I'm an occupational therapist and work with a team including physiotherapists and speech and language therapists. Many of my patients have deteriorating conditions. I am astounded by how few of them receive CHC funding, even when they are near the end of their lives. Being a health professional, I know what the NHS CHC criteria are and I won't complete a checklist unless I believe someone qualifies. We don't want to put these people through the lengthy assessment process if they are not likely to get a positive result.

We used to have a local CHC team, but then it got centralised and moved out of our area. Since then things have gone really downhill. The first major problem is that the nurse assessors often don't tell us when the assessments are taking place. We only find out about them if we are told by chance, often by a patient or family member. We know that nurse assessors often assess people on their own and make decisions on eligibility. This should not be happening.

When we do attend assessments it can be extremely hard to make the nurse assessors understand why someone has complex health needs. I was recently working with a gentleman who had PSP. He couldn't move and needed hoisting everywhere. His condition meant he often didn't remember this limitation so he would often try to stand and then fall over. He had awful swallowing problems, where he had so much saliva it got into his lungs. This meant his mouth was constantly having to be cleared. He was fed through a tube eight times a day. His wife was providing all his essential care.

I was part of the MDT that graded him at the highest level for nearly half of the categories in the DST, which should have meant he qualified for NHS CHC.

When the case was reviewed the nurse assessor said he wasn't eligible. We couldn't believe it. They said they disagreed with how unpredictable his needs were. His application was rejected. We appealed the decision but he passed away two months later.

It's vital that the treating professionals who see the person on a monthly basis and really understand their condition are listened to. In my experience the opinion of the nurse assessor has overruled other MDT members. It's incredibly frustrating for us, and really distressing for the people involved.

What needs to happen?

- CCGs must ensure that MDTs always meet the minimum requirements of the National Framework, particularly in respect of including “those who have an up-to-date knowledge of the individual's needs, potential and aspirations”⁵. Ideally this would apply to all the health and social care professionals involved in the care and treatment of the individual.
- CCGs must involve professionals with condition-specific expertise – preferably in person, or where this isn't possible by requesting evidence and advice in advance – and demonstrably give due regard to this professional judgement.
- CCGs must ensure that the professional judgement of all MDT members is given equal weight alongside ensuring that nurse assessors fulfil the co-ordination role described in the National Framework, and do not inappropriately overrule other members of the MDT.
- CCGs must demonstrate that the person being assessed (where possible) and their carers are involved in the assessment and their opinions are given due regard.
- Professionals from the local authority must be aware at what level they are able to offer support for people. If the person's healthcare needs exceed the level that the local authority can lawfully provide for, they should then be eligible for NHS CHC. This should be made explicit by professionals and be clearly documented.

⁵ [National framework for NHS continuing healthcare and NHS funded nursing care](#) (Nov 2012) Annex A

Dysfunctional decisions: how the Decision Support Tool is used

The Decision Support Tool (DST) is the nationally mandated tool for assessing whether an individual's healthcare needs place them beyond what the local authority can legally provide. If their needs are high enough they should be eligible for NHS CHC. Completing the DST involves looking at the individual's care needs across 12 broad areas of care (care domains) and allocating a level of need in each. The care domains are designed to help assessors identify healthcare needs across a wide range of conditions. In each domain, examples are given that would typically represent the different levels of need.

Positive progress

- The creation of the checklist and DST as part of the National Framework has meant that everyone is technically measured against the same criteria. However, in practice we know this assessment process is largely dependent on the team conducting the assessment.
- The four key indicators form part of the DST. This is a particularly important measurement for those who have cognitive impairments or fluctuating conditions.
- The NHS CHC operating model and assurance framework were created to:
 - improve the application of the DST assessment
 - measure CCG performance to improve consistency of assessments and outcomes across CCGs
 - use Quality Surveillance Groups to hold CCGs to account
 - involve the NHS England Directorate of Commissioning Operations to hold CCGs to account
- The DST allows someone to be assessed if they don't have any health needs, but instead have extremely challenging behaviour. This is a positive change, but sadly is not often taken into account.

However it's not only these scores that determine if the individual is eligible for NHS CHC. Professionals should also use the four key indicators where relevant.

The key indicators refer to the four key characteristics of need including nature, intensity, complexity and unpredictability. Each of the four key indicators may alone, or in combination, indicate a primary health need. The MDT should use their professional judgement to consider the combined need identified across the domains and indicators.

Pamela Coughlan case

THE LAW

In 1999 Pamela Coughlan went to court after the NHS attempted to stop funding her care and pass it over to the local authority. She was tetraplegic, but could use a computer with voice technology and an electric wheelchair independently.

The court ruled that her healthcare needs were significant enough to be beyond what a local authority could reasonably be expected to provide, and were therefore the responsibility of the NHS.

Pamela Coughlan's case is significant because the health needs they identified were not that substantial.

The key question that the court had to decide was where the boundary between the responsibilities of a local authority and the NHS lies. In other words, how much care does an individual need in order to qualify for NHS CHC?

Pamela Coughlan's court case made case law. This should mean that if an individual has higher needs than Pamela Coughlan, but doesn't meet every threshold on the DST, they should still qualify.

Current challenges

- **80%** of professionals surveyed said the DST was not fit for purpose, or there was room for improvement in some areas.
- **73%** of survey respondents who applied for NHS CHC felt the DST did not ask relevant questions to elicit an accurate impression of a person's situation.
- Despite explicit guidance⁶ to the contrary, there is evidence that assessors use the DST tool mechanistically, and do not apply their own professional judgment. The examples given in the DST often represent extreme failures, or an absence of appropriate care and support. These examples can prejudice assessors by artificially raising the eligibility threshold and making them believe people have to be worse than they do in reality. For example:
 - In the nutrition domain the descriptions of what would constitute a severe level of need are “unable to take food and drink by mouth. All nutritional requirements taken by artificial means requiring ongoing skilled professional intervention or monitoring over a 24 hour period to ensure nutrition/hydration, for example I.V. fluids **or** unable to take food and drink by mouth, intervention inappropriate or impossible.” If this description is used as a benchmark by the assessment team, the person being assessed would have to be at the point of death in order to qualify. This is not the threshold at which CHC is intended to be made available

The DST is a guide. The court has set the level at which someone must receive NHS CHC. In the Pamela Coughlan judgment the judge decided that if healthcare is more than ‘incidental or ancillary’ it falls into the healthcare category rather than social care.

- People with well managed needs are often assessed as being ineligible despite having needs that qualify. The DST can often be used to measure the failure of care, rather than the care needs of the person. For example, if

someone has serious bed sores where their skin has broken, this would qualify. Someone with the same health needs who was being regularly moved by trained professionals to avoid bed sores would, under this incorrect interpretation, not necessarily qualify.

- Some professionals have shared their frustration that less attention is paid to the four key indicators. It is absolutely crucial these are factored into the final decision. For example, if someone scored lower in one of the domains, they could still be found eligible based on the unpredictability and complexity of their needs.
- When being assessed someone's diagnosis should not be relevant. The assessment should be purely based on their needs. Despite this, the alliance hears evidence from people who tell us that they have been refused NHS CHC because their needs are a routine part of their condition(s) and its or their progression. Assessors therefore conclude, incorrectly, that those needs are outside the scope of NHS CHC.
- The alliance has seen situations where someone is assessed as having no emotional or psychological needs because they have a cognitive impairment which means they communicate differently.
- When an MDT makes a recommendation that someone should receive NHS CHC, the CCG should sign it off unless there are exceptional circumstances which should be for a clearly articulated reason. Such reasons can include missing evidence, or major differences between the evidence and the recommendation. However, the alliance knows that sometimes CCGs say that exceptional circumstances are simply that they disagree with the decision. This is not how the guidance should be interpreted. **35%** of survey respondents told us they had experienced the MDT awarding eligibility, only to have that rejected by the review panel. If this represents the numbers being turned down for that reason, these can in no way be considered exceptional.

⁶ [National framework for NHS continuing healthcare and NHS funded nursing care](#) (Nov 2012) paragraph 88

Alison's experience

“ My father-in-law, Tom, was an intelligent and independent man with an amazing memory. He graduated from Oxford, was an Artillery Instructor during the war, and then became a teacher. At 96, his health was going downhill. He had several mini strokes and developed vascular dementia. I enquired about applying for NHS CHC. I knew about it because I've been a nurse for more than 40 years.

An assessment took place while Tom was living in a nearby care home. At the time of the assessment he had no short-term memory, was immobile, deaf and partially sighted. He couldn't feed or wash himself, and he had a catheter fitted as he couldn't go to the loo. Having a catheter made him vulnerable to infection, so he often required medical attention to deal with that. He couldn't eat or drink independently and had lost lots of weight.

During the assessment they used the DST to assess the severity of Tom's needs. The criteria can be interpreted differently by the people conducting the assessment. I believe the team assessing Tom manipulated some of the information. For example, when assessing his mobility they decided that because he could shuffle about in bed, he was mobile and therefore did not qualify. What's their definition of mobility?



He couldn't walk, stand or even turn over in bed, which I think means he was immobile. It was very clear to me that the assessment was a sham. It was awful to watch. Tom was completely reliant on others to provide his care. I felt the assessors seriously downplayed most of his problems.

Our application was turned down. If he wasn't eligible, I don't know who would be! We appealed their decision several times, and were finally successful four days before Tom passed away.

As well as being very concerned professionally by how this process was conducted, I worry about my own future as I have MND. The thought of being assessed through this process myself is terrifying.

What needs to happen?

- The checklist and Decision Support Tool should be rewritten so they more effectively measure individuals' healthcare needs against the lawful limit of care that the local authority can provide.
- CCGs and local authorities must ensure all staff who deal with NHS CHC have thorough training to understand the lawful limit of care that the local authority can provide regarding healthcare, as defined in the Coughlan judgment. The training should be mandatory.
- Until the assessment tools are rewritten, MDTs must adhere to the National Framework by not using the current tools mechanistically. Instead assessors must use the key indicators and their professional judgment⁷ when deciding on an individual's eligibility for NHS CHC.

⁷ [National framework for NHS continuing healthcare and NHS funded nursing care](#) (Nov 2012) paragraph 88

Why are we waiting? The delays experienced by people applying

In the past there was no substantive guidance on timelines for the NHS CHC process which meant that many people were kept waiting weeks or months for a result.

Positive progress

- The National Framework gives clear guidelines to all CCGs and local authorities on the timelines that should be followed. It makes clear that the time between the checklist being received and the decision being made shouldn't exceed 28 days.
- The National Framework introduced a fast track pathway tool so that someone who is in very poor health, and near the end of their life, can have their eligibility determined as quickly as possible.

Sue's experience

“ My dad was a district surveyor for the City of London and cared for my mum who had colitis and suffered a stroke. Sadly he's not in a good way himself now so I've been trying to get him NHS CHC. He has dementia, rectal cancer, stage 4 kidney disease, a poor heart, and is totally incontinent.

The process of applying for NHS CHC has been really distressing. We've experienced huge delays, it's been appalling! We didn't receive a written decision on dad's application for 21 months.

We asked for the checklist to be done in April 2014, but they didn't come for three months. Following the checklist, they agreed dad should have a full assessment, and we assumed this would happen quickly.

Dad finally had the assessment in March 2015 – 11 months after the checklist had been completed. When it was over, the nurse assessor told us that she was going to recommend dad be turned down.

We knew we wanted to appeal the decision, however we couldn't begin this process until we had the official outcome in writing. We didn't get the negative confirmation until January 2016. That is 10 months after the assessment, just to receive the letter confirming it was a no.

I rang the local CHC team every month, only to be told each time that they had a backlog. The delays were dreadful, and we weren't told what was happening at any stage.

This whole process has really affected our family emotionally. The system is so time consuming. It takes ages to read all the information and analyse it.





Current challenges

- We know from people applying, and professionals, that the 28 day timeline is rarely achieved. **42%** of survey respondents who had applied for NHS CHC told us they waited more than 28 days to receive the final decision regarding eligibility. On top of this they were not kept well informed of the new timescales.
- Almost **20%** of professionals who responded to our survey told us that the decision timeline never, or almost never, adhered to the 28 day timeframe. Alongside this people are sometimes unaware that the countdown should start from the checklist referral, rather than when the MDT conducts the first full assessment.
- From more than 100 responses, only 14 CCGs told us they kept within the 28 day timeframe. In 2015/16 one CCG reported it didn't conduct someone's assessment for **255** days after receiving the checklist. It is unacceptable that anyone should wait this long, particularly since their health and wellbeing will often be deteriorating.
- Many individuals made reference to being told about a backlog as a reason for the delay in their decision. This backlog can often be as long as **18** months.
- The alliance has seen examples of people in hospital getting a more timely assessment, at the expense of people in care homes or with an existing care package.
- The alliance has been contacted by many people who have told us that their fast track assessments were not processed quickly, and sometimes these delays have resulted in people passing away before being assessed. This stands in stark contrast to the Government's policy focus around people having a choice about the care they receive towards the end of their life, and its commitment to support people to die at home.
- Applications for fast track assessments are sometimes being rejected⁸. There are reports that the 'rapidly deteriorating' criteria in the fast track assessment tool⁹ is being interpreted to mean anything from 12 weeks to two weeks, and anyone thought to live longer than that is being rejected for this assessment. To be eligible for fast track, it is not necessary to predict the time left until the patient dies.
- The alliance knows that there is sometimes a general confusion about the use of fast track, with the assumption that it is only available for people with cancer. This is not the case.

⁸ People have shared this experience with many of the organisations represented within the alliance. It is also mentioned in Macmillan's report, [Can we live with how we're dying?](#)

⁹ [Fast track pathway tool for NHS continuing healthcare](#)

Natalie's experience

“ Dad had MND and it was progressing fast. He couldn't talk at all or convey expression through his face. He couldn't move, so had to be hoisted. He was fed through a tube into his stomach, couldn't go to the toilet and his breathing was compromised. I moved dad in with me, and was caring for him while trying to work full time. It was a lot of pressure.

Our district nurse was really supportive, and requested a fast track NHS CHC assessment for us. She made the request just before New Year.

At this time our palliative care consultant said she didn't think dad had long to live. Despite this, the

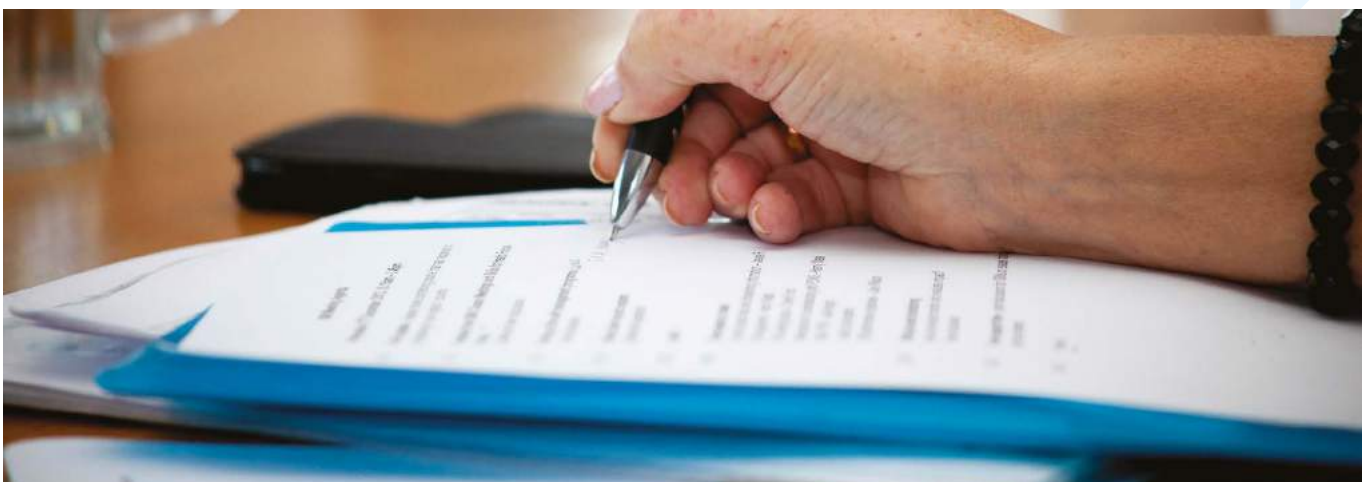
assessment didn't happen quickly, and took place in mid-February. I experienced so much worry and anxiety during this time, as I waited to find out whether he would be eligible. Though logically, I didn't know how much more could have been wrong with him in order to make him qualify.

When the assessor finally came, it was clear to me she didn't know anything specific about MND. She said they should only be doing fast track assessments for someone who is end of stage and then followed that by saying, 'which he clearly is not'. Dad died two days later.



What needs to happen?

- CCGs must stick to the time frames for providing an assessment and the result. If they are unable to do this they should proactively contact the applicant or their representatives to explain the delay and provide a revised timeline.
- NHS England must strengthen sanctions against professionals, CCGs or local authorities who refuse fast track applications.
- To reduce delays in the future, greater investment is needed to allow CCGs and local authorities to recruit more professionals to co-ordinate and undertake NHS CHC and assessments.



Righting the wrongs: the appeals process

Appealing a decision about NHS CHC can be time consuming, complex and distressing. Often people can wait months and even years. During that time, it is likely that individuals are paying for care unnecessarily and also engaging solicitors to support them through the process. In England, there are three stages people can go through:

Local appeal

This is the first stage of the appeals process. There are very few guidelines in the National Framework about this. As a result, CCGs conduct these meetings in very different ways. Some CCGs offer informal meetings to get people's points of view, others conduct a panel stage if there is a significant complaint, while some do a half hour telephone call. The appeals process should be dealt

with within three months, but the alliance knows it can sometimes take more than a year just to complete the local stage. It's hugely variable.

Independent review panel (IRP)

The IRP is governed by NHS England and we have heard mainly positive feedback on the way these are conducted. There are usually three decision makers including an independent lay chair (often an academic or legal person who has gone through training on this), a health professional and a social care professional (who can't be from the same CCG who made the decision). The professionals should all work together to make a decision, and often seek the advice of a clinician and specialist in the condition of the person applying.

Parliamentary and Health Service Ombudsman (PHSO)

People can contact the PHSO if they have exhausted all other appeal routes.

Current challenges

- The person applying, or their family and friends, often need information and advice around the appeals process. Yet **55%** of professionals who completed our survey said they did not feel confident giving people information on how to appeal decisions.
- IRPs cannot overturn the original eligibility decision – all they can do is advise the CCG that they should change their mind. CCGs can technically ignore this instruction, though the National Framework says they have to have a good reason to continue to say no.
- Worryingly, some people admitted they resolved their appeals by accepting less than the full amount to which they were entitled.
- The alliance knows from speaking to people that many decide not to appeal their decision on NHS CHC eligibility. This is not because they feel the decision was correct, but because they are too distressed and exhausted to go through the complex appeals process.

What needs to happen?

- NHS England must ensure that CCGs adhere to the appeals timescales as laid down in the Department of Health guidance¹⁰.
- When appeals are upheld, care costs incurred must be repaid in full.
- Training should be improved to ensure that professionals know how to direct someone towards the NHS CHC appeal process, and can explain the system comprehensively.
- NHS England must monitor the outcomes of the local appeal process. If they are consistently proven to be unduly lengthy, or not impartial, individuals should be able to bypass this stage and proceed straight to the IRP.

¹⁰ [National framework for NHS continuing healthcare and NHS funded nursing care](#) (Nov 2012) paragraph 95



“ I'd always been fit and healthy, running every other day, doing martial arts, and being a member of the Territorial Army. I'd never had a broken bone! Having been self-employed for over 30 years, I only ever had a handful of days off sick. My life changed when I went on holiday and fell down a flight of stairs. I ended up with a severe spinal cord injury (SCI). I now rely on a wheelchair and need 24 hour support for even basic tasks like going to the toilet, washing and eating.

Following an assessment, my MDT recommended that I receive NHS CHC. We thought this decision would be approved by my CCG. I couldn't believe it when they came back and said no.

The CCG didn't accept the scores I'd been given and thought my case had been over stated. But they didn't provide any reasoning for their comments, and had never met me. We challenged the outcome, and the CCG came back saying they were deferring their decision. Without a definite yes or no I couldn't officially appeal. This situation went on for months. I believe it was a delaying tactic.

It was such a distressing time. Two years earlier there was nothing wrong with me. Now I was fighting a complicated system I knew little about, in a situation I didn't want to be in, far from home. I can see why people give up. It's an uphill

struggle, you go round in circles and no one takes responsibility. After much chasing, the CCG confirmed I wouldn't be given NHS CHC. I took my case to local appeal but the CCG chose who would sit on the panel, and unsurprisingly they came up with the same decision.

I then said I wanted to take it to an IRP. The CCG told me I had to apply for this through them, so I did. Nothing happened for three months. After chasing my CCG they admitted they had got the information wrong and I actually had to go directly to NHS England. So my appeal hadn't moved forward at all and I only found out because I kept calling and eventually someone told me. Once in touch with the IRP organisers, they thought I had a good case. They decided to uphold my appeal and requested my CCG grant NHS CHC. Even after this, the CCG didn't provide help straight away. If the CCG refuses to adhere to the IRP's ruling only the courts can enforce the decision. It doesn't seem like they are accountable to anyone.

Without NHS CHC in place I couldn't go back to my house. From the time of my accident, I had been kept in a specialist spinal unit and then moved to a residential care home. I had expected to be home after a few months, but I didn't go home for more than three years. My whole experience of this process was simply appalling.

Who cares and how much? The provision of care

Once someone has navigated this complex process and been awarded NHS CHC, the CCG is required to commission a package of care. A growing area of concern for the Continuing Healthcare Alliance is the lack of suitable care packages put in place once eligibility for NHS CHC has been granted.

Positive progress

- NHS England has stated that personalisation and choice are priorities for them¹¹. This focus ties into NHS CHC because care packages should be focused on the individual and their needs and aspirations, not just the cost of care.

¹¹NHS England (Oct 2014) 'Empowering patients' [Five Year Forward View](#); p12.

What needs to happen?

- Where an individual has been found eligible for NHS CHC, the CCG should demonstrate that:
 - they have conducted a comprehensive assessment of the individual's health and social care needs and offered a package of care sufficient to meet all of these
 - they have taken all possible steps to ensure that the individual's preferences have been met by the package of care they are offering
 - the package of care offered compliments the current national agenda of personalised healthcare provision¹²
 - the package of care is needs driven and not purely based on financial considerations

¹²NHS England (Oct 2014) 'Empowering patients' [Five Year Forward View](#); p12.



Marie's experience

“Dad was a carpenter, and had always been very active. When he reached his eighties, completely out of the blue his health went downhill fast. He stopped being able to stand up and we got a diagnosis of MND that was a huge shock. Within a week of us knowing anything was wrong we were having to make some really big decisions. It was traumatic. Someone at the hospital told us about NHS CHC and helped dad get a fast track assessment. Dad was found eligible and the CCG said they would fund his care. He wanted to go back home so we tried to investigate what needed to be done to make this possible.

The next day I got a call from someone telling me that they had just visited my dad, without any of the family present, and he now wanted to go into a nursing home. I just didn't think this sounded right as he'd never said anything like that to me. When I saw dad that evening he started talking about not wanting to be a burden, which again he'd never said before. We spoke to the people from the CCG who were supposed to arrange his NHS CHC package and they said that if he stayed in his own home they would only be able to pay for four care visits a day. We asked what he was supposed to do overnight and they agreed he wouldn't be safe. It was confusing because they knew he couldn't cope with only four visits a day, but their job was to provide the care he needed. I feel like dad was forced into a nursing home because the CCG wouldn't pay for the care he needed in his own home. We should have been told what the options were to help him live independently. He was given no choice.

Current challenges

- In some geographical locations, funding for these care packages can take a long time to come through.
- The National Framework promotes individual choice and control, but only requires CCGs to provide packages of care that they consider to be appropriate. This creates a problem between assessed needs and reasonable needs. People can be told they are eligible, and then allocated less care than they have been paying for independently. For example, someone may have been paying for 24 hour care themselves, and then the CCG grants NHS CHC but deems two hours a day satisfactory. Members of the alliance believe that CCGs have a duty to meet all of the individuals' assessed care and support needs.
- When less funding is received patients can be forced to transfer to a different care provider, resulting in the loss of professional carers who the person and their family know and trust.
- For some people, residential care and nursing homes provide a really positive option for their ongoing care. However this choice should be made by the individual and their family. Despite this, some CCGs have introduced policies that force people into residential care if the cost of their care at home is more expensive. Of those who responded to our FOI request, **19** CCGs admitted to already having a policy in place that caps the cost of a care at home package. The lowest cap in 2015-2016 was just **£614.97** per week, meaning anyone whose care at home package cost more than that would be forced to live in a care home whether they wanted to or not. To maintain positive health and wellbeing, CCGs should prioritise keeping someone at home if that is their preference. The alliance believes that forcing people into residential care could become a huge problem.
- Many long-term conditions require a high level of specialist care that some care homes are unable to provide. People can then be asked to leave residential care because their needs cannot be met.
- Personal Health Budgets (PHBs) were introduced to give people choice and control over the care they need. However **53%** of survey respondents said they were not offered a PHB, with a further **22%** saying they weren't sure if they were offered one or not. When assigned incorrectly, PHBs can mean even more pressure is placed on the person applying for support and those close to them.
- Almost **20%** of survey respondents who were awarded CHC said the cost of their care was not met by their NHS funding, resulting in them having to pay top-up fees. Without these top-up fees, more people would end up in increasingly dangerous situations. As an NHS service, CHC should not allow top-ups.



Say that again: the impact of regular reassessments

Having gone through the long and complex process of applying for, and often appealing decisions about, NHS CHC, it is unacceptable that people are then continually reassessed.

From our survey results, of the people successfully awarded NHS CHC, **44%** had gone through at least one reassessment. Most local areas insist on reassessing people at least annually. Our FOI found that between April 2015 and March 2016 one CCG withdrew funding from **241** people following a reassessment. There are occasions where withdrawing NHS CHC can be justified (if a person's health needs have reduced). However many people being reassessed are in the advanced stage of their condition, and often near the end of their life with little room for improvement.

As well as being an incredibly anxious time for the person being reassessed, and those close to them, we also believe that reassessments are a drain on resources.

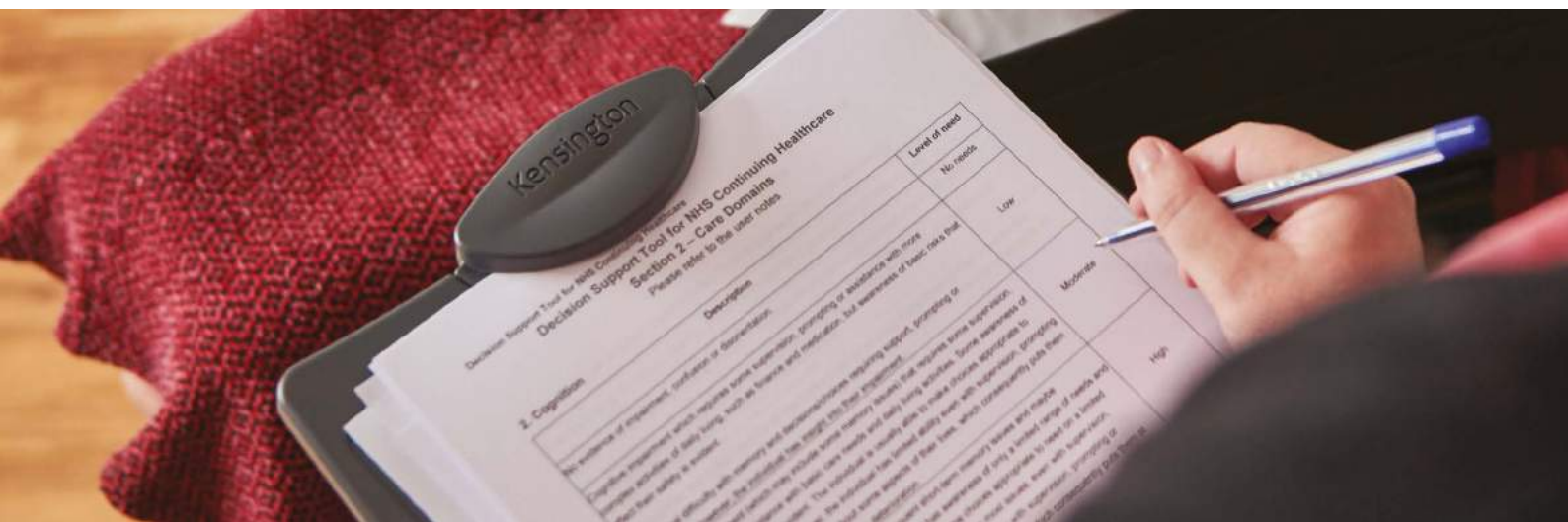
With professionals across the country struggling to stay on top of their ever increasing workloads, unnecessary reassessments add to this¹³.

This view was echoed in the Public Accounts Committee (PAC) report *Personal budgets in social care* (2016) that said annual reviews “may be too rigid and therefore an unnecessary cost for local authorities” and recommended that the Department of Health review this.

¹³Public Accounts Committee (2016) [Personal budgets in social care](#).

Current challenges

- Some people with well managed needs are having their care withdrawn, with no acknowledgement given to how their needs will progress without a suitable level of care in place.
- The National Framework states that when reassessing someone's eligibility, MDTs must reference the previously completed DST and prove that things have changed. The alliance knows from speaking to people that this often doesn't happen. The situation is compounded by completed DSTs not being shared with the person or their representatives, denying them the ability to refer to it at a later date.
- Many people who have been reassessed shared their feelings of concern and distress with the alliance. Having NHS CHC funding withdrawn can mean care packages are reduced or removed altogether. With many people unable to afford equivalent care packages themselves, the person in need of care can be put at risk.
- People with dementia are commonly reassessed regularly. Despite having a progressive condition, funding is often removed when someone goes from having problem behaviour to being more withdrawn, or moves from being at risk of falls to being bed bound. This is despite other health needs emerging as a result of these changing circumstances.



Graham's experience

“ I visit my wife Maureen each day at a nearby nursing home. She has advanced Parkinson's and severe dementia.

Maureen can't stand up or walk, she has a tremor which makes her whole body shake and sometimes this means she can't even sit in a chair without falling off.

She can't communicate and often feels anxious. She can't feed herself and is completely reliant on the carers and nurses helping her.

Being blind myself, getting all of the information collated for the assessments can be a challenge.

But I worked hard to ensure Maureen was fairly assessed for NHS CHC, and our application was successful, which was a huge relief.

However, I soon discovered that we would have to go through this long and complex process on a yearly basis. It doesn't make any sense. Maureen will not get better – her condition is progressive.

As the years go by, her care needs will stay the same or increase. Despite this, during each reassessment I know that the new assessor will take a different view, and Maureen's care could be stopped.

Each time we approach Maureen's annual review, the thought that we could lose NHS CHC is at the forefront of my mind.

Reassessments can go on for between three and four hours. Surely it must be a waste of money to reassess people who will never improve?

I know Maureen might need more care in the future, but to face the possibility of her care being removed is somewhat cruel. It's a very distressing and exhausting time for me.

I honestly don't know what we'd do if her support was cut off.



Michelle's experience

“ As a social worker one of the most challenging aspects of my involvement in NHS CHC is when funding is withdrawn following a reassessment, and the person is referred to adult social care.



Funding is stopped within 28 days of the reassessment, leaving families very little time to adjust. Sometimes I believe people lose out when they shouldn't, but alternatively there can be occasions where the decision to withdraw NHS CHC funding is the right one. Regardless of whether it's right or wrong, people are often totally confused about what has happened, as they may feel like their health condition hasn't improved or stabilised. The packages of care paid for by CHC are often extremely expensive, and far above anything that could be funded by the local authority.

This means social workers have to drastically cut the care given to individuals. This can result in a lot of anger being directed at the social worker. Additionally, the care agency that had been paid for by NHS CHC would often have to be withdrawn as the social services department doesn't have the budget to fund the same care package.

So in really bad scenarios people end up having their care cut, and also losing trusted carers who they have a relationship with. This burden is often felt most harshly by the friends and family who provide care, as they are forced to fill the gaps.

What needs to happen?

- NHS England must introduce an option for professionals to select if they agree that someone should not be re-assessed 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.
- CCGs must demonstrate that, where regular reviews are conducted, the focus is not purely on the individual's ongoing eligibility for NHS CHC, but, as directed in the National Framework, focused on whether the care package continues to be appropriate¹⁴.
- Where ongoing eligibility for NHS CHC is considered, previously conducted assessments must be available and assessors should demonstrate a reduction in healthcare needs in order to justify withdrawing eligibility¹⁵.
- Where NHS CHC funding is withdrawn, and individuals are transferred onto a local authority funded social care package, local authorities must provide adequate funding to meet eligible needs. They shouldn't impose arbitrary cost ceilings that result in people being forced into residential care against their will.

^{14,15} [National framework for NHS continuing healthcare and NHS funded nursing care](#) (Nov 2012) paragraph 139.

Never the same: the lack of consistency and consequences



As so many decisions regarding NHS CHC are made at a local level, people across the country have very different experiences and outcomes.

Some areas have NHS CHC teams based at the CCG or local authority who help co-ordinate the process. In other areas these teams don't exist and health and care professionals are required to take control of this process on top of their other tasks.

The National Framework has tried to reduce these variations, but we know they still exist. It is unacceptable for someone's location to have an impact on whether they qualify for this much-needed support.

In order to see clear improvements, it is vital that there are consequences for organisations who do not comply with NHS CHC guidance.

Positive progress

- NHS England developed the CCG Assurance Framework, which lays out how CCGs should perform. It strengthens the requirement for CCGs to follow the NHS CHC National Framework and includes 'I' statements that were contributed by stakeholder organisations. The aim of this framework is to improve the performance of CCGs. However it is not a legal requirement – it is a set of guidelines.
- If there are persistent problems NHS England has local area teams who can approach poorly performing CCGs.

Current challenges

- The operating model and Assurance Framework may not be the most effective tools to ensure that CCGs assess people correctly and make lawful decisions on eligibility. CCGs have to deliver NHS CHC, however they could say they are delivering it properly with no one ensuring this is taking place in reality. NHS England is responsible for ensuring CCGs apply the checklist, fast track pathway and DST properly, but how they ensure this is not clear.
- NHS England has limited sanction over CCGs who perform poorly.

What needs to happen?

- NHS England must establish an improved system for monitoring CCG performance against the National Framework, guidance and timelines for eligibility decision making.
- NHS CHC must constitute a more significant component when CCGs are having their performance measured.

Kathy's experience

“ I got into this sector because I believe people should receive the help and support they need. Sadly, there are significant variations across the country when applying the National Framework. In my area I think the processes are designed to keep people out and I really believe decisions are being based on financial ulterior motives and not on the patient's needs.

In order to complete a DST professionals and care providers are contacted for evidence. A deadline of 28 days is set for feedback. If no information is received, or if some reports are not submitted within this timeframe, the case is closed.

This penalises patients, and sometimes their applications are not progressed to the assessment stage, through no fault of their own. If the CCG does receive evidence to support the claim, they cherry pick bits from the professionals which gives a distorted reflection of the patient, and this seldom results in eligibility.

I've also seen panels come together and downgrade the MDT findings – despite the fact

they've never seen the person. My CCG rarely find anyone eligible. An example of another major problem is the role of the assessor/co-ordinator. Some local areas have someone whose job it is to co-ordinate the assessments.

That person is a health professional, usually a nurse, but shouldn't form part of the MDT. They are supposed to be an impartial resource. But in my area this person gives the patient a score, and sometimes even has their opinion rated more important than others. I have been in situations where the MDT members recommend that someone is eligible, and the co-ordinator says no and the patient is rejected.

I want people in my location to be confident that they can have their health needs assessed fairly. Despite raising serious concerns to NHS England, very little has been done to address the many issues in my area.

In the meantime my colleagues and I continue to battle on, in the hope that one day things will become less challenging.



Filling in the blanks: improving the data that is gathered

In order to improve something, we need to know what is wrong. This is hard to prove when it comes to NHS CHC as so little data is collected. At the moment the only data required is from people who have been successfully awarded NHS CHC. This means we know nothing about all of those who were unsuccessful. We don't know how long they waited for an assessment, why they were unsuccessful, or if they appealed. We know that healthcare professionals have huge demands on their time, but it is essential that accurate information around NHS CHC is recorded so the system can be improved, and problematic areas can be tackled.

Positive progress

- CCGs now deliver more in-depth data. NHS England has employed a team of people to collect and produce data on NHS CHC. The data is more comprehensive than anything produced before, and provides quarterly stats split down by individual CCG but also geographical areas. They ask CCGs to provide information on:
 - the number of patients newly eligible during the quarter – this is a unique count of new patients granted eligibility during the quarter
 - the number of patients eligible at the end of the quarter (snapshot activity)
 - this is a unique count of patients eligible for NHS CHC on the last date of the reporting quarter

Current challenges

- CCGs don't have to report on condition-specific data. It is essential to have this. For example, if data shows that people with advanced Parkinson's are constantly found ineligible, this could be tackled with more training for professionals on the condition.
- CCGs are asked to report from the date a decision is made and not the date the funding starts. This makes it hard to tell how quickly individuals receive the funding package and care is put in place. We know from people applying that this part of the process can take a significant amount of time.
- When the number of people being awarded CHC has decreased, it is not clear if this is because people have passed away, or people previously eligible have been reassessed and their care has been withdrawn.

What needs to happen?

- NHS England must require information about the condition(s) of the person being assessed for NHS CHC.
- CCGs should report how many people have had eligibility for NHS CHC withdrawn when being reassessed.
- NHS England must request and publish CCGs data on:
 - the total number of NHS CHC applications (whether successful or not)
 - the total number of NHS CHC awards
 - the total number of appeals against decisions of ineligibility
 - the total number of ineligibility decisions overturned at local appeal
 - the total number of ineligibility decisions overturned at independent review panel
 - the total number of ineligibility decisions referred to the PHSO



Vision for the future

The NHS in England is experiencing huge financial challenges and organisational change. In relation to CHC, the implementation of the *Five Year Forward View* is likely to have significant consequences.

NHS England has divided the country into areas that will develop Sustainability and Transformation Plans (STPs). These new STP areas will likely become a new tier of leadership and decision making within the NHS. At the same time, new care models are being developed, including Primary and Acute Care Systems (PACS) that may take ultimate responsibility for organising a person's care along the whole pathway.

As CCGs struggle to shape whole health economies effectively, many are joining forces in order to cover larger footprints. Alongside this, if the new PACS model takes on responsibility for planning care, CCGs may no longer be required to perform one of their key roles. These new models are expected to be fully developed, and rolling out across England, by 2020.

Regional devolution is also having an impact. Some emerging devolved arrangements seem keen to integrate their social care responsibilities with NHS structures. For example, in Greater Manchester, the Salford Royal Foundation Trust is being transformed into an integrated care organisation and has taken on responsibility for social care. Similar initiatives to this will likely take place elsewhere. In addition, NHS England is keen to integrate specialised and locally-commissioned

services, with a move to co-commissioning and place-based commissioning. Though we can't be clear exactly how these changes will impact the future of CHC, the system will look considerably different. Whatever form CHC takes, the failures we've identified in this report should be considered when trying to create new structures that don't repeat the mistakes of the past. From our conclusions, there are important questions that must be considered when devising the future operation of NHS CHC:

- Should responsibility for NHS CHC continue to rest with CCGs in its entirety, or even at all?
- Where would it fit within the new care models – should a combination of PACS, STP areas or new devolved authorities take on responsibility?
- Will the use of capitated budgets by the PACS model, if it is implemented, lead to a more proportionate and responsive implementation of NHS CHC, ensuring that people can be properly supported while avoiding needless crises?

This is not an exhaustive list but shows some of the questions that NHS CHC will face going forward. We urge NHS England and the Department of Health to consider how CHC will operate in the NHS after the implementation of the *Five Year Forward View*, and prepare to make the necessary changes. Patients should be closely consulted during this process to ensure the system operates effectively, and does not continue to be blighted by the failings identified in this report.

Conclusion

Everybody who applies for NHS CHC is likely to have significant needs and be subject to extreme vulnerability. The process has massive implications for the person, their wellbeing and that of their family and friends. Speaking to people across the country has shown that though there are pockets of good practice, in many areas people are still facing major problems when interacting with NHS CHC.

Many are given little information about the system, and are not updated on the progress of their application. The 28 day decision timeline is rarely adhered to, and appeals can take vast amounts of time with little communication during this process. Reassessments put people through unnecessary stress, while those successfully awarded NHS CHC are often left to deal with care packages that do not meet their needs. The alliance has seen a lack of expertise regarding decision making, and in extreme situations a complete disregard for the current legal framework. With CHC being squeezed, and many people being deemed ineligible, CCGs face the possibility of expensive acute care further down the line.



Key recommendations

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

It's essential that rapid and robust changes are made to improve the current system. As changes to the health and social care system in general develop and take shape, the Continuing Healthcare Alliance wishes to support NHS England and the Department of Health to ensure that, whatever the new system looks like, no one is left without the care they so desperately need.

Appendix 1

Key problems and recommendations from the *Failing to care* inquiry (2013)

Key problems in 2013	Recommendations of 2013 Inquiry	Positive progress since 2013
A lack of local NHS performance data meant that the Department of Health was unable to tell if and where issues occurred. The lack of monitoring and enforcement also meant that they didn't take action to resolve problems.	To understand and meet the demand for these services by collecting condition-specific data at every stage of the process for those applying for NHS CHC.	<p>April 2015 – NHS England published the NHS CHC Assurance Framework that commits them to collecting more robust data on the system, which was one of the chief asks of the <i>Failing to Care</i> Inquiry. NHS recruited data analysts to drive this forward and have made commitments to expand the amount of data collected to better hold CCGs to account for poor performance.</p> <p>April 2016 – NHS changed the requirements of data that must be provided by CCGs to increase the availability of data concerning NHS CHC. The data is more comprehensive than anything produced before, and provides quarterly stats split down by individual CCG but also areas.</p>
In 21% of cases there were clear examples of existing national guidance not being followed, with no repercussions for breaching these guidelines.	End uncertainty for those involved in assessments by establishing an improved National Framework with clear processes, guidance and timelines for decision making. These should be applied by Clinical Commissioning Groups who are held to account by NHS England for their performance.	<p>2013 – Primary Care Trusts were replaced by CCGs who became responsible for implementing the National Framework alongside the NHS Commissioning Board. It's their responsibility to assess people, commission services and review applications. With this in mind, the Department of Health published a revision to the Framework, practice guidance and the three tools in November 2012.</p> <p>April 2015 – NHS England published the NHS CHC Assurance Framework and Operating Model.</p> <p>October 2014 – Parkinson's UK, as representatives of the Alliance, met with the Minister for Care and Support at the time, Norman Lamb, to discuss progress made by the Department of Health and NHS England. Following suggestions from Parkinson's UK, he pressed his Department to look into the possibility of establish financial incentives for good performance and penalties for poor performance.</p>
Due to lengthy processes, people with Parkinson's were dying whilst waiting for their health board to make a decision on whether they were eligible.	Implement an assessment process that reflects the needs of people with complex and fluctuating conditions, including assessments that involve healthcare professionals with expertise in that condition.	
59% of assessments did not involve a professional with specialist expertise or knowledge in the condition leading to inaccurate and incorrect decisions.	Give vulnerable individuals a voice by developing a truly independent review process to consider complaints or appeals against decisions. And if these decisions are upheld, ensure that care costs incurred are repaid in full.	As above.
40% of people going through the assessment process reported experiencing a lack of empathy and transparency from professionals in the decision making process and when appealing a decision.		

Key problems and recommendations from the Failing to care inquiry (2013)

Key problems in 2013	Recommendations of 2013 Inquiry	Positive progress since 2013
24% of people with Parkinson's were continually reassessed, despite living with a progressive condition.	Reduce anxiety for those worried their care will be taken away with an agreement that applicants with a progressive condition – or one that will never change – should not be continually reassessed for eligibility.	April 2014 – The Continuing Healthcare Alliance wrote to the Minister for Care and Support calling for an end to reassessing those with progressive and non-improving conditions. Over 1,000 emails were sent to Norman Lamb's backing this call. However, the Minister was unmoved and there has been no policy change despite follow up letters to his office.
Health and social care professionals we spoke to admitted the system is so complex they have difficulty following the correct process.	Ensure sick and vulnerable people are able to navigate the difficult assessment process by giving them the right to experienced and independent support.	<p>October 2014 – Owing to lobbying from alliance members, alongside other organisations, there was a specific mention of advocacy in relation to the provision of NHS continuing care in the Care Act Guidance.</p> <p>October 2014 – NHS England confirmed they would invest in developing an electronic navigation tool for those trying to apply for NHS CHC.</p> <p>September 2015 – NHS England created a national NHS continuing healthcare information and advice service that provides 90 minutes of free and independent advice to help navigate the system.</p>

Appendices 2-4: Evidence

We conducted two surveys to gather opinions on the current state of NHS CHC:

Appendix 2 Survey for individuals

A survey for individuals who had applied for NHS CHC themselves, or friends or family who had applied on behalf of someone else.

Open between: April 2016 and July 2016

Responses: 274

Appendix 3 Survey for professionals

A survey for professionals who work in the NHS CHC system.

Open between: May 2016 and July 2016

Responses: 409

Appendix 4 Freedom of Information Request (FOI)

We sent an FOI to all CCGs in England asking for information about various aspects of NHS CHC. We made the request in May 2016.

- 129 CCGs responded out of 213
- Of the 129 responses we received, many CCGs said our request would take too long to collate the information so provided limited answers to certain questions.

Appendices 2-4: Evidence *continued*

Questions

1. For each of the years from April 2013 to March 2016, please supply the total number of applications made to your Clinical Commissioning Group (CCG) for NHS continuing healthcare funding that proceeded past the initial checklist stage to a full assessment of needs.
2. For each of the years from April 2013 to March 2016, please tell us the total number of applications for NHS continuing healthcare your CCG refused following a full assessment of needs.
3. For each of the years from April 2013 to March 2016, please tell us:
 - The number of requests made for a local review following a decision by your CCG of ineligibility for NHS continuing healthcare funding.
 - The number of decisions your CCG made resulting in ineligibility for NHS continuing healthcare that were overturned at the local review.
 - The number of decisions your CCG made of ineligibility for NHS continuing healthcare that were upheld at the local review.
 - The number of requests made to your CCG for an independent review panel following a local review upholding a decision of ineligibility for NHS continuing healthcare.
 - The number of decisions of ineligibility for NHS continuing healthcare made by your CCG that were overturned at the independent review panel.
 - The number of decisions of ineligibility for NHS continuing healthcare made by your CCG that were upheld at the independent review panel.
 - The number of decisions of ineligibility for NHS continuing healthcare made by your CCG referred to the Parliamentary and Health Services Ombudsman.
 - The number of decisions of ineligibility made by your CCG that were overturned by the Ombudsman, with NHS continuing healthcare funding then being awarded.
 - The number of decisions of ineligibility for NHS continuing healthcare made by your CCG that were upheld by the Ombudsman.
4. For each of the years April 2013 to March 2014, April 2014 to March 2015 and April 2015 to March 2016, please tell us: What is the median time taken by your CCG to conduct NHS continuing healthcare assessments, from receiving the initial checklist to notifying the applicant of the eligibility result?
5. Does your CCG always involve experts in the assessment of the specific medical condition that the person being assessed for NHS continuing healthcare presents with? For example a Parkinson's nurse, an MS specialist nurse, a neurologist etc.
6. We know that people with long term, progressive conditions who are found eligible for NHS continuing healthcare are often reassessed after a set period. For each of the years April 2013 to March 2016, please supply:
 - The total number of NHS continuing healthcare reviews conducted by your CCG, on people who have existing eligibility. Please include all reviews including 3 month and annual.
 - The total number of cases in your CCG where NHS continuing healthcare eligibility was withdrawn following the review of a person previously found eligible for NHS continuing healthcare.
7. For each of the years from April 2013 to March 2016 please give us the numbers relating to how many people receive NHS continuing healthcare in each of the locations listed below, across the area your CCG covers.
 - In their own home • In a residential care home • In a hospice
 - In a nursing home • Other, please specify
8. Does your CCG have a policy that would, in all but exceptional circumstances, cap the cost of a care at home package against the equivalent cost of a residential care package?
 - a. Yes/No b. If so, please tell us the cap amount for:
 - i. April 2013 to March 2014 ii. April 2014 to March 2015 iii. April 2015 to March 2016

Full copies available on request.

The Continuing Healthcare Alliance

The Continuing Healthcare Alliance (formally known as the Failing to Care Coalition) is a group of charities and professional bodies who work together to improve NHS CHC for the patients and professionals who come into contact with it. The alliance is currently made up of 13 members including:



Care and support
through terminal illness



PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

Sue Ryder



www.continuinghealthcarealliance.co.uk
continuinghealthcarealliance@gmail.com



@CHC_alliance