



# NHS continuing healthcare in Gateshead and Newcastle

## About Healthwatch Gateshead and Healthwatch Newcastle

Healthwatch Gateshead and Healthwatch Newcastle are two of 152 local Healthwatch organisations established throughout England on 1 April 2013 under the provisions of the Health and Social Care Act 2012. We have a dual role to champion the rights of users of publicly funded health and social care services for both adults and children, and to hold the system to account for how well it engages with the public.

We collect feedback on services from people of all ages and from all communities. We do this through our network of voluntary and community sector organisations; during events, drop-in sessions and listening events at a range of venues across Gateshead and Newcastle; online through the feedback centre on our websites; via social media; and from callers to our information and signposting helplines. As part of the remit to gather views, we also have the power to 'enter and view' services and conduct announced and unannounced visits.

Healthwatch Gateshead and Healthwatch Newcastle are part of Tell Us North CIC (company no. 10394966).

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## Executive summary

Healthwatch Gateshead and Healthwatch Newcastle have gathered views and experiences from people and their carers who have been through the NHS continuing healthcare (CHC) process, and from representatives of voluntary and community sector organisations. We used various methods to achieve this, including working with partners in NHS Newcastle Gateshead Clinical Commissioning Group (CCG) and Newcastle and Gateshead councils, as well as with service users and their carers, and the voluntary and community sector. We also asked people to complete a survey to give direct feedback on their experiences.

Our intention is that this information will be used by providers and commissioners to help them improve the CHC journey for people and their carers.

We learnt that, overall, people found the process complicated and that it lacked information to help them through the process. In some cases expectations were unfairly raised about the possibility of receiving CHC funding. We noted that people generally did not understand the financial implications of CHC funding. There were also issues around lack of consistency in how the CHC framework was being interpreted by nursing assessors. Furthermore, there appears to be significant variation across Newcastle and Gateshead around the hospital discharge process for people waiting for a CHC funding decision.

Although this work looked at the adult CHC process, we also discovered that children and young people were not being referred for assessments within the recommended timescales.

We have made recommendations based on our research in the following areas:

1. Information
2. Quality assurance of CHC assessments
3. Getting regular feedback from patients and their carers
4. Children in transition into adult services

Further details can be found in the 'Recommendations' section of this report.

## About NHS continuing healthcare

NHS continuing healthcare (CHC) is a package of care provided outside of hospital, arranged and funded solely by the NHS, for individuals aged 18 years and older who have significant ongoing healthcare needs. When someone is assessed as eligible for CHC the NHS is responsible for funding the full package of health and social care. The number of people assessed as eligible for CHC nationally has been growing by an average of 6.4% per year over the last four years and in 2015–16 almost 160,000 people received or were assessed as eligible for CHC.

Funding levels range from 28 to 356 people per 50,000 population, with significant variation in levels of eligibility for CHC funding between different clinical commissioning groups (the organisations that plan and fund healthcare).

This has been recognised by a recent Audit Office report ‘Investigation into NHS continuing healthcare funding’<sup>1</sup> and in a Public Accounts Committee report published in January 2018<sup>2</sup>. The committee report says the government must take steps to improve the funding and assessment process for people with continuing healthcare needs, calling it a ‘complex process beset with delays and poor-quality assessments’.

### **Funded nursing care**

NHS-funded nursing care is care provided by a registered nurse for people who live in a care home. The NHS pays a flat rate contribution directly to the care home towards the cost of this registered nursing care.

### **Children and young people in transition into adult services**

The national framework for NHS continuing healthcare and NHS-funded nursing care tells us that children’s services should identify those young people for whom it is likely that adult CHC will be necessary and should notify whichever clinical commissioning group (CCG) will have responsibility for them as adults.



This should occur when a young person reaches the age of 14 and be followed up by a formal referral for screening at age 16. At the age of 17, eligibility for adult CHC should be determined in principle by the relevant CCG so that effective packages of care can be commissioned in time for when the individual reaches the age of 18 (or later, if it is agreed that it will be more appropriate for responsibility to be transferred then).

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<sup>1</sup> <https://tinyurl.com/CHC-investigation>

<sup>2</sup> <https://tinyurl.com/funding-failing>

## NHS continuing healthcare locally

Newcastle Gateshead Clinical Commissioning Group (CCG) is responsible for the delivery of CHC across the Newcastle and Gateshead area.

The first step to CHC is the NHS continuing healthcare checklist. This is a screening tool to help identify those people who are eligible for a full assessment for NHS continuing healthcare. This initial checklist can be completed by a variety of professionals which may include:

- GPs
- Doctors
- Nurses
- Social care workers
- Care home managers

After a checklist has been completed and accepted for further assessment, a nursing assessor will carry out a full assessment using the decision support tool (DST)<sup>3</sup>. This is normally done within 28 days of the checklist submission and not usually in a hospital setting.

The final decision is made by a multi-disciplinary team which includes:

- Nurse co-ordinator – representing Newcastle Gateshead CCG
- Clinical lead – representing Newcastle Gateshead CCG
- Adult Social Care Manager – representing the local authority

## Discharge procedures from Newcastle and Gateshead hospitals for people who may be eligible for CHC

It appears that discharge practice for patients who may be eligible for CHC varies across Gateshead and Newcastle.

### Gateshead

Gateshead Health NHS Foundation Trust told us that it has an ongoing training programme for staff led by the discharge liaison team. This focusses on identifying patients who may be eligible for CHC and how to complete and submit a CHC checklist.

Adult social care in Gateshead told us that if a person is waiting for a CHC assessment and a home has been identified (this is usually a nursing home), the discharge will go ahead without waiting for a decision from the CHC multi-disciplinary team (MDT).

The local authority will meet any extra costs until a final decision regarding CHC has been made. However, a financial assessment towards social care costs would need to take place, or if a person had been previously assessed as paying contributions this would continue until the decision on CHC is made.

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<sup>3</sup> Checklist and the decision support tool can be found at <https://tinyurl.com/CHC-tools>

If the MDT recommends CHC, the award is backdated to the day the person was discharged from hospital to the nursing home or other home setting. Any money that has been paid by the local authority is reimbursed by Newcastle Gateshead CCG and the local authority will reimburse any contribution that the person has made following their financial assessment.

If the decision is that the person is not eligible for CHC then funded nursing care will be applicable from the start of the relevant care. Therefore, the council and service user continue to pay their contributions to the home.

## **Newcastle**

Newcastle Hospitals NHS Foundation Trust told us that Newcastle Gateshead CCG had previously funded a post to train staff at the trust on CHC eligibility and how to complete and submit a CHC checklist. The funding was for two years and ended in June 2017.

They also told us that there can be delays to a discharge when the patient has complex needs and is waiting a full CHC assessment. Any funding that needs to be met in the interim which is over and above the normal local authority spending, must be agreed by the CCG before the patient can be discharged.

Adult social care in Newcastle told us that they will meet any assessed care needs costs, to speed up hospital discharge, until a final CHC decision has been made. This includes residential and nursing care admissions and most discharges back to a person's home.

If the MDT recommends CHC, the award is backdated to the day the person was discharged from hospital to the nursing home or other home setting. Any money that has been paid by the local authority is reimbursed by Newcastle Gateshead CCG and the local authority will reimburse any contribution that the person has made following their financial assessment.

If the decision is that the person is not eligible for CHC then funded nursing care will be applicable from the start of the relevant care in the case of a nursing home placement. The council and service user would continue to pay their contributions to the home/domiciliary care fees.

## **The fast track pathway**

A person can be fast tracked for CHC if that person has a rapidly deteriorating condition and the condition may be entering a terminal phase. The person may need CHC funding to enable their needs to be urgently met (for example, to enable them to go home to die or to provide appropriate end of life support either in their own home or in a care setting). In this case the CCG should action this immediately.

## The purpose of our review

Both Healthwatch Gateshead and Healthwatch Newcastle had received reports from service users, and their relatives and carers, about issues with CHC. These included delayed decision-making regarding funding, decisions not to fund, delays to hospital discharge and lack of information to support families through the CHC process. The Committees that lead both Healthwatch decided that this would be a priority for 2017–18, for both Newcastle and Gateshead.

This research did not include children and young people's continuing care<sup>4</sup>. We did however, look at young people in transition into adult services who may be eligible for CHC, some of whom had received NHS funding as a child.

## What we did

### Working with the voluntary and community sector



We wanted to find out about the issues in more detail and organised an event under the banner of 'One collective voice' to hear from the voluntary and community sector (VCS) and other organisations that support people to access services, information, support or guidance around the CHC process.

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<sup>4</sup> <https://tinyurl.com/CCnationalframework>



There was representation from the following organisations:

- Advocacy Centre North
- Dementia Care
- Disability North
- Gateshead Access Panel
- Newcastle Council for Voluntary Service
- Independent Complaints Advocacy
- Parents in Power
- The Advice Centre – Gateshead
- The Carers Trust
- Newcastle Upon Tyne Hospitals NHS Foundation Trust

## Initial findings

Representatives from the above organisations told us that they were aware of issues around the CHC process including:

- Families feeling they are excluded from the process
- Lack of information
- Inconsistency around professional input at decision support tool assessments
- Inequality in the process
- Issues around transition from children and young people's continuing care to adult CHC

The findings from the event, added to initial service user, relative and carer feedback, helped us to shape the questions for a survey. We wanted to see how the local processes and experiences matched or differed from CHC nationally. The following topics were identified:

- Information
- Hospital discharge
- Initial screening
- Full assessment using the decision support tool
- Outcome
- Appeals

We also asked colleagues at the 'One collective voice' event if they had any comments or suggestions that they wished to share. Some of their comments included:

**“Adult social care workers sometimes make assumptions about where a person will end up and their ability to self-fund (prior to CHC decision) and place people in places based on their assumption to pay costs.”**

**“Social workers are making assumptions that people will not be eligible for CHC.”**

“It can be pot luck as to whether you get a good social worker who understands CHC.”

“Family members should be encouraged to attend meetings or someone who knows the patient.”

“Relatives don’t have the right kind of information about CHC and think they will automatically qualify for CHC if they pass the checklist stage.”

“Families can get very distressed when the outcome is no and can’t take it.”

“There appears to be a variation of the way forms are filled in.”

“There appears to be inequality in the process – it depends on resources, energy and articulation and knowledge of the family.”

“If the family is articulate they have more chance of being successful in challenging decisions.”

“Advocates should be available for family or person at the DST; people can feel intimidated.”

“There seems to be a high turnover of nurse assessors.”

“Some nurse assessors appear to be unfamiliar with the CHC framework.”

## **Healthwatch observation of a full assessment by CCG nursing assessors**

We were invited to observe, with the families’ permission, two assessments carried out by CCG nursing assessors using the Department of Health decision support tool (DST). Both were children in transition to adult services in Gateshead. This work was facilitated by the transitions team at Gateshead Council.

We requested the transition protocol from both Newcastle and Gateshead local authority transition teams and noted that Gateshead’s protocol referred to the CHC pathway, but Newcastle’s did not.

### **What we observed**

The first DST assessment was done outside term time and met the 28-day target set by the Department of Health CHC framework. However, this meant that people involved in the person’s care at school were not available to attend the full DST assessment.

The DST identifies twelve areas of need or 'domains'. The 12th domain allows for other significant care needs to be taken into consideration, and was used in one of the assessments as it had been raised by the family. It was not used in the other case that we observed.



In one observation, the DST assessed the need as being 'met' because the carer was meeting the need. However, the framework states that 'the reasons given for a decision should not be based on the fact that a need is well managed'.

Both cases we observed had been triggered by the transition team (not children's services) and took place after the person's 18th birthday, which is not in line with the Department of Health CHC framework guidelines on transition.

The framework states that financial issues should not be considered when deciding an individual's eligibility for NHS continuing healthcare. However, if the local authority is providing social care to an adult, a financial assessment is triggered to assess any client contribution. Therefore, in many cases a financial assessment comes before the DST assessment, which is contrary to the framework.

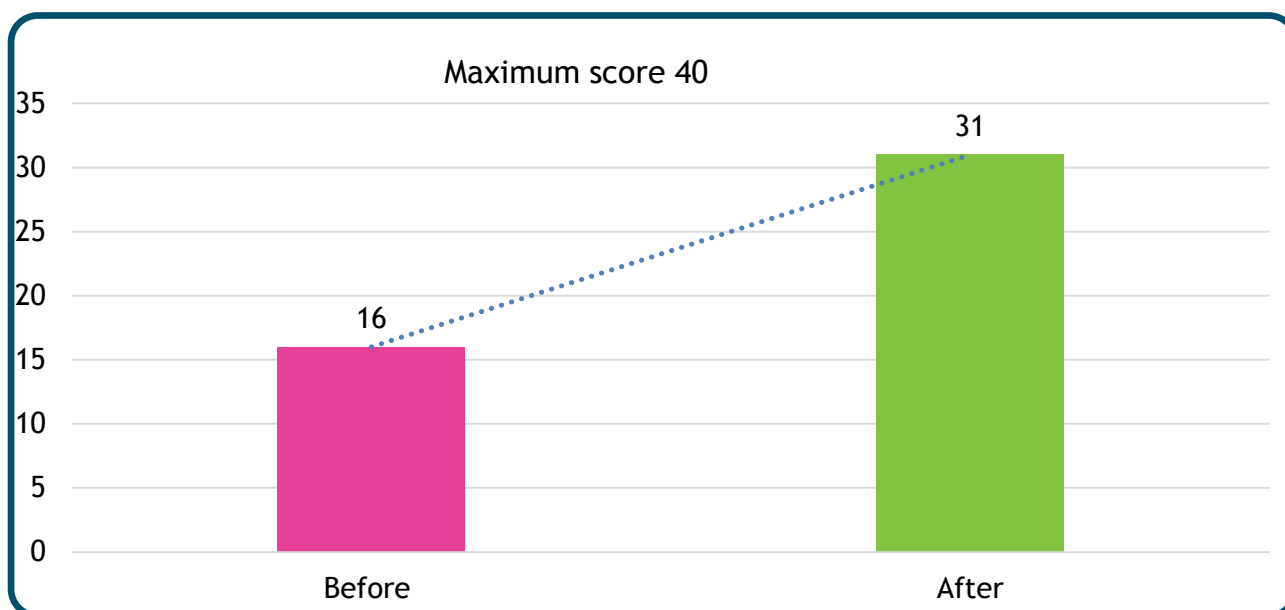
## Information assessment: working with Healthwatch Champions

We wanted to find out what information was currently available locally and nationally on CHC. We worked with the Newcastle Gateshead CCG engagement lead who told us that the CCG was currently looking to produce information locally to support service users and carers through the CHC journey.

During the course of our research we discovered national information on CHC, in the form of a film, commissioned by NHS England to help explain the national policy framework to people and their families.

Healthwatch Champions are our trained volunteers who support us with our engagement and research work. We held a workshop with eight Champions to try to gauge the quality of the information.

We asked them to rate their knowledge of CHC from one to five before watching the film. The combined points were 16 out of a possible 40. We repeated the question after the Champions had watched the film and those numbers rose to 31 out of 40 (93.7% increase).



### Champion feedback

“Simple language. Difficult subject but made much easier to understand. The repetitive language gives a consistent message.”

“Would probably like to see the video again to increase knowledge of CHC even more.”

“Film really helpful in understanding CHC.”

“Some aspects of CHC would need to have more than a second look to understand more fully.”

**“I think the video needs to be advertised and localised. This would be really useful for the community.”**

**“Most of the BAME community access information online as we can use translation services, the film may be able to be translated.”**

The film and the findings from the workshop were shared with the CCG and it was agreed that the film would be a useful tool. This is now available on the CCG website at [www.newcastlegatesheadccg.nhs.uk/your-health/continuing-healthcare](http://www.newcastlegatesheadccg.nhs.uk/your-health/continuing-healthcare)

There is also an option to include local information, which the CCG has agreed to consider.

## **The service user survey**

We prepared a survey based on the information we had already collected from VCS organisations, service users and their carers. We wanted to hear from people, and their relatives and carers, who had been through the process in the past 12 months so that their information would be current. We approached Newcastle Gateshead CCG to see if it could assist in identifying people and distributing a paper version of the survey on our behalf. Unfortunately, the CCG was unable to help on this occasion due to capacity issues. So reaching our target participants was more challenging.

The survey was conducted over a three-month period from October to December 2017. We shared the survey with a wide range of organisations, including those who were involved in ‘One collective voice’. It was advertised in the Healthwatch Gateshead and Newcastle newsletters with contact details for those who wanted further information or a paper version, and offering help in completing the survey where required. We also paid for extra promotion on social media to help us reach as many people as possible.

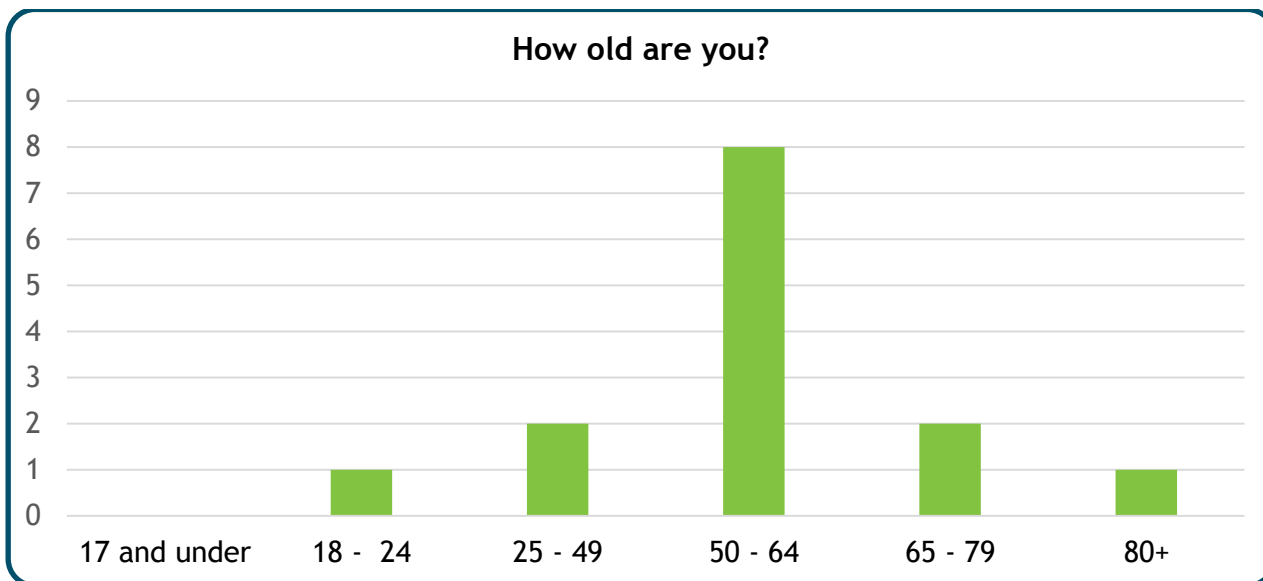
### **Who responded?**

In total there were 40 responses to the survey which equates to approximately 11% of the people who went through a full assessment in 2016–17. We cannot tell if the data is a true reflection of the situation across Newcastle and Gateshead; all we can say is that it represents the views of those people who completed the surveys.

Because we wanted to capture different elements of the CHC assessment journey, not all the sections of the survey were applicable to everyone. Therefore the numbers of people responding to the questions decreased as the questionnaire progressed from the initial information section to the appeal stage.

## Demographics

There were 14 responses to the following question.

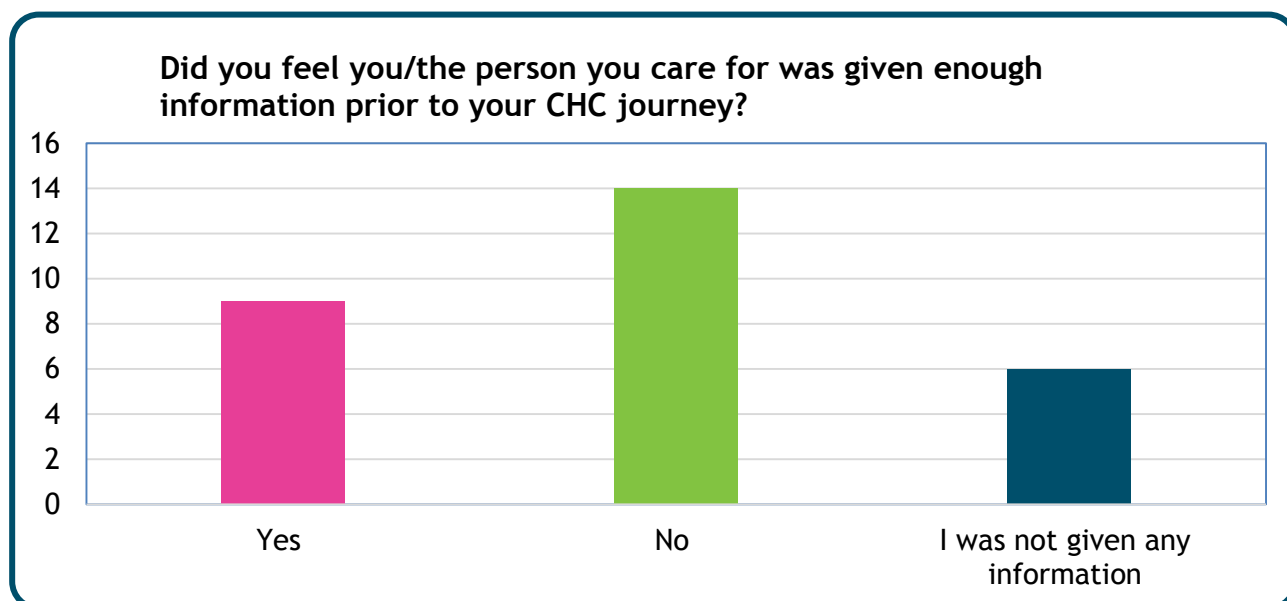


Ten of 14 respondents to the demographics question told us they were carers. Nine of the 14 respondents said that they identified as female and five as male. Nine respondents were from Gateshead and five were from Newcastle. Twenty six respondents chose not to answer this question.

## Our findings

### Information at the checklist stage

We began by asking about information that people may have received at the initial checklist stage of their CHC journey. We wanted to know how informed people felt they were about the CHC process and if they understood how the final decision on eligibility could impact financially on patients, carers and their families.



Of the 29 people who responded to this question, nine people told us that they/the person they care for, were given enough information at the assessment stage.

However, 14 people thought they did not receive enough information and rated the information they received as 2.7 out of 10. Six people told us that they were not given any information at this stage of the journey.

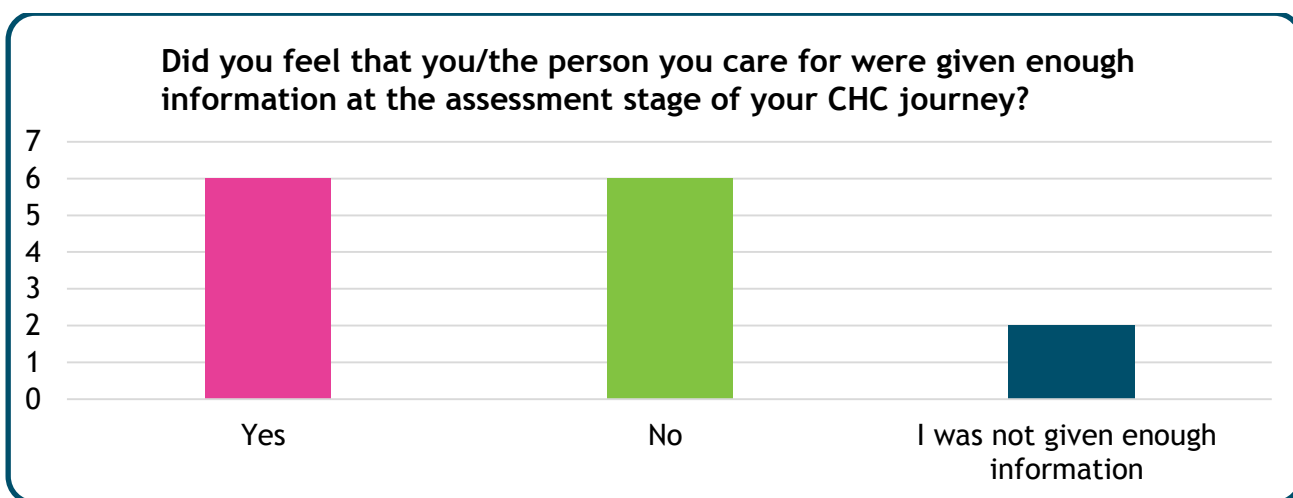
**“Information provided was through care home and not CHC. All other information was sourced online before application process was started.”**

**“It should be openly advertised on wards and in surgeries. It seems it is up to professional staff to decide whether a person can claim this or not”**

**“Had we been made aware of this funding it would have made a huge difference to the quality of my Mother’s last few weeks of life.”**

### Information at the full assessment stage

A full assessment is when a nurse assessor, on behalf of the CCG, carries out a full assessment using the decision support tool (DST) which is part of the Department of Health framework. We asked people if they thought they had received enough information prior to their full CHC assessment.

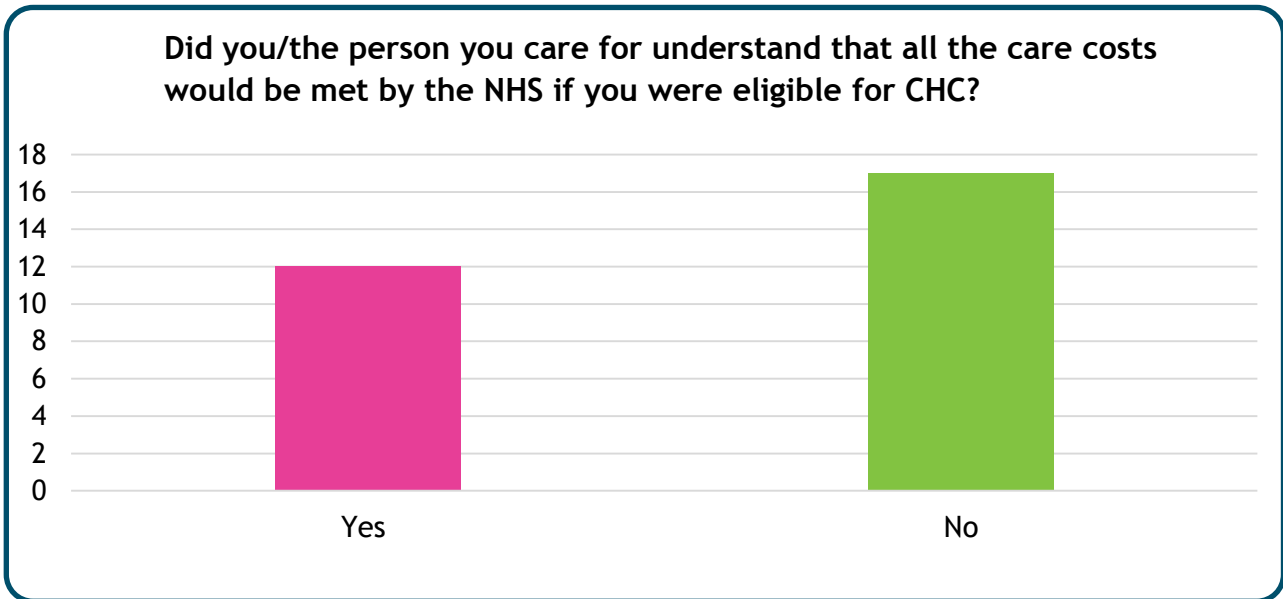


Of the 14 people who responded to this question, six told us that they felt they had received enough information, six said they did not and two respondents said they were not given any information at this stage of the process.

**“We had no information to help us through. We didn’t understand what was happening.”**

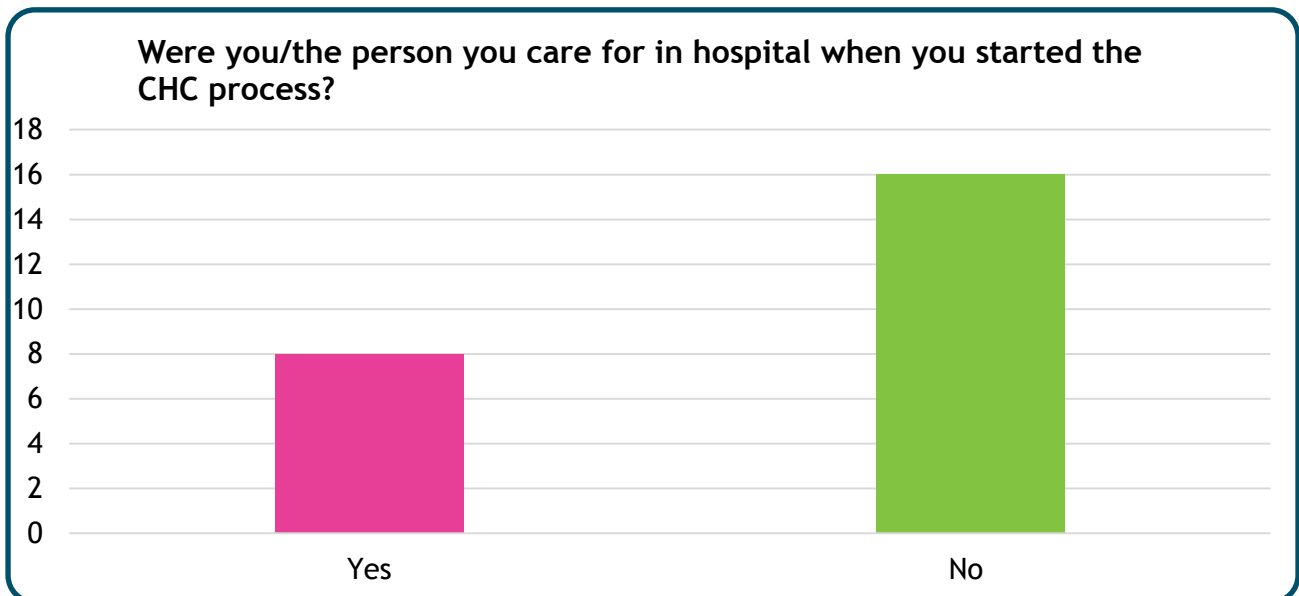
## Understanding the implications of CHC funding

Of the 29 people who responded to this question, 17 people did not understand that all the care costs would be met by the NHS and 12 people told us that they did understand.



## Hospital discharge and the CHC process

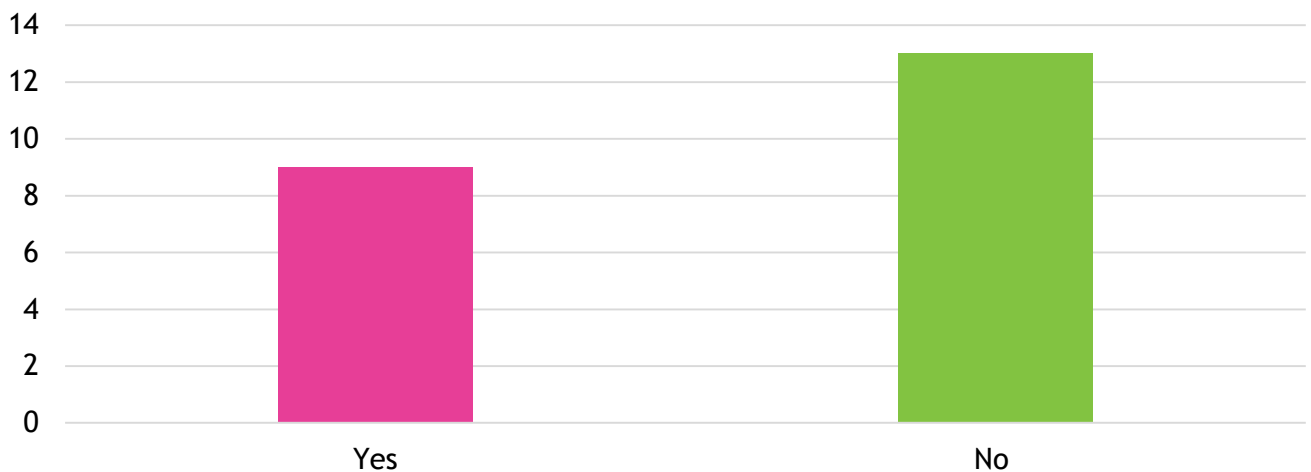
We wanted to find out if there were delays to hospital discharge due to the CHC assessment process and whether this varied across Gateshead and Newcastle hospitals.



Eight of the 24 respondents were in hospital when their CHC journey began: six in a Gateshead hospital and two in a Newcastle hospital. Three people were fast-tracked, one from Gateshead and two from Newcastle.



### Was the discharge from hospital for yourself/the person you care for delayed because you were waiting for a decision on CHC?



Twenty-two people answered this question. Of the nine respondents who told us their discharge was delayed; three were from Newcastle hospitals and six from Gateshead. Thirteen respondents told us they were not delayed, six from Newcastle and six from Gateshead with one from another hospital.

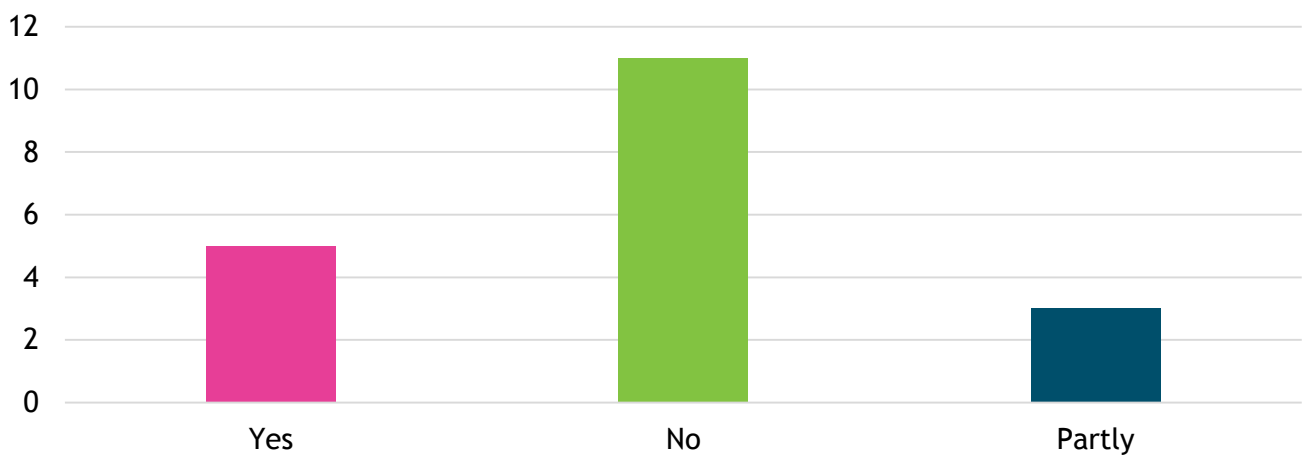
### Initial checklist screening

Nineteen people responded to the question. Of these, five respondents told us that they had felt fully involved, three told us that they had felt partly involved in the initial checklist stage and 11 stated that they had not felt involved.

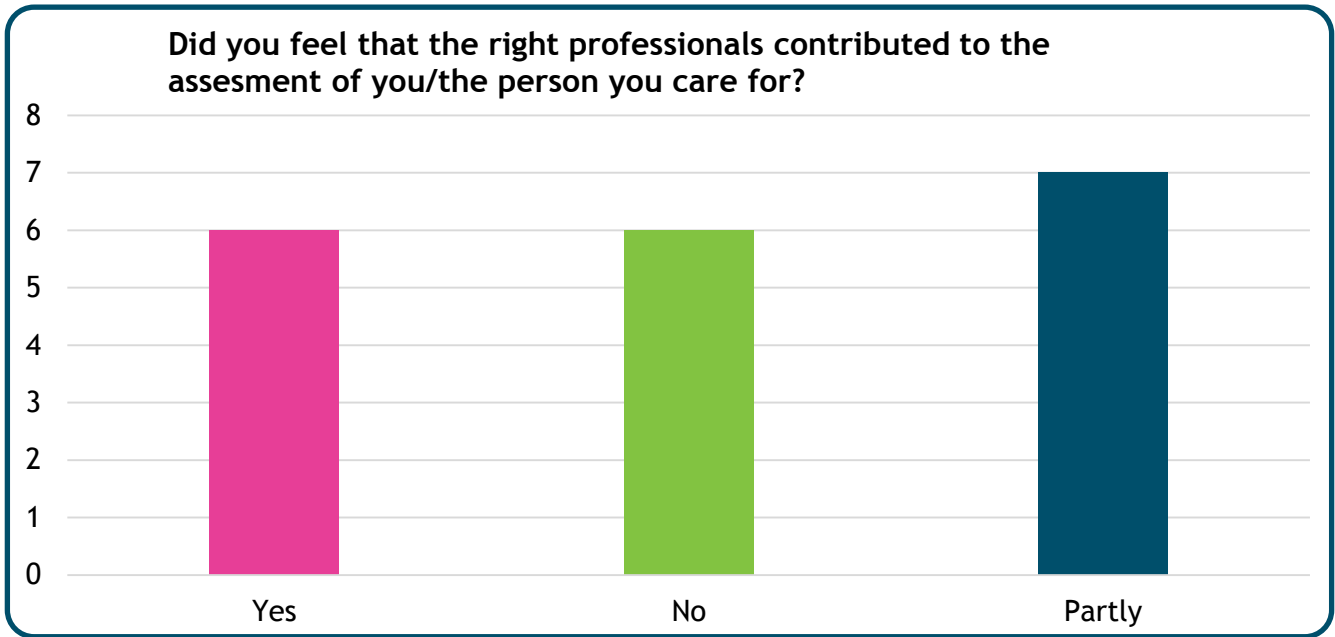
**“Lack of confidence in the process with road blocks applied from the outset.”**

**“I was only involved in the decision later once hospital decided.”**

### Did you feel that you/the person you care for were fully involved in the initial checklist stage?

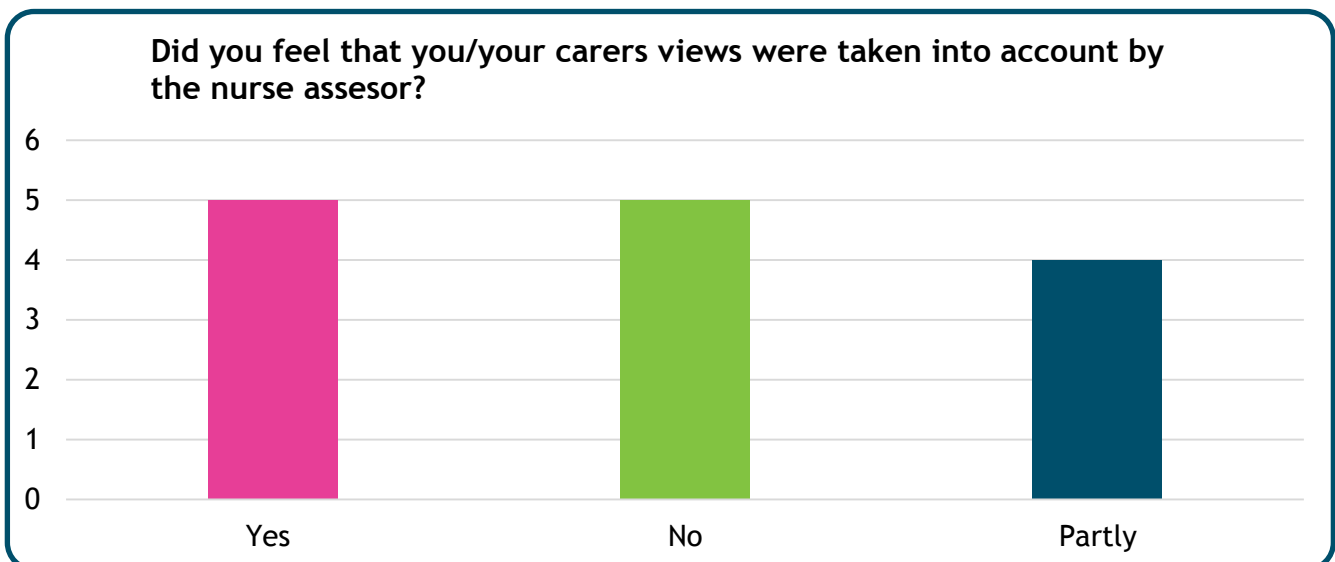


## Full assessment decision support tool (DST)



There were 19 respondents to this question: six respondents said that they felt that the right professionals contributed to the assessment. However, 13 respondents told us that they either had not, or only partly, felt that the right professionals had been involved in the full DST assessment.

**“The DST is not easily understood by non-medical professional and is not fit for purpose as the purpose appears to ensure that correct criteria cannot be met.”**

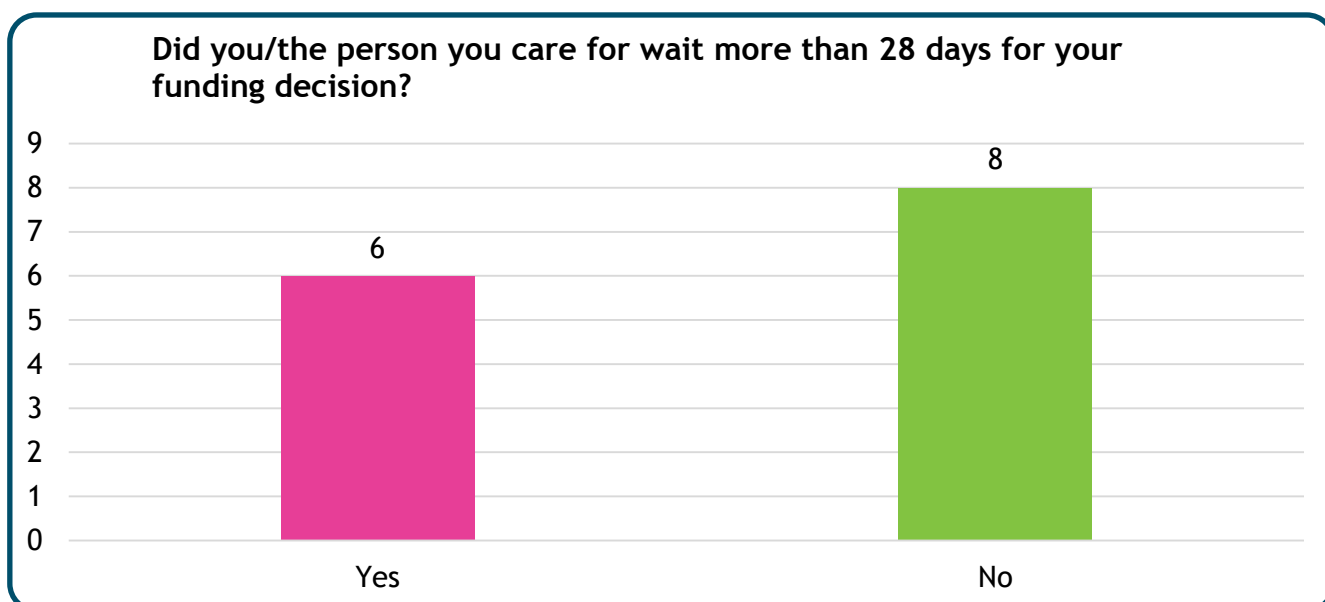


There were 14 respondents to this question. Five said that they felt that their views were taken into account, four felt their views were partly taken into account and five did not feel that their views were taken into account by the nurse assessor.

“There were so many conflicting influences and people involved – it was very stressful.”

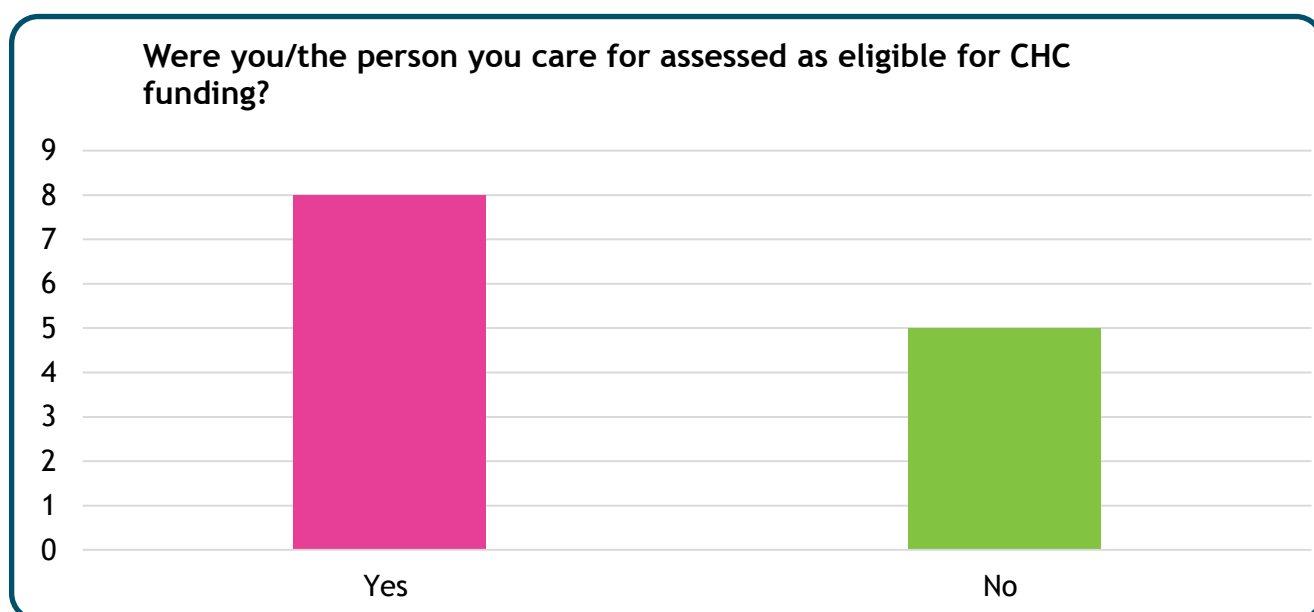
“It was the most horrible and traumatic experience of my life.”

## Outcome



Fourteen people responded to the question and eight respondents said that they received their decision within 28 days.

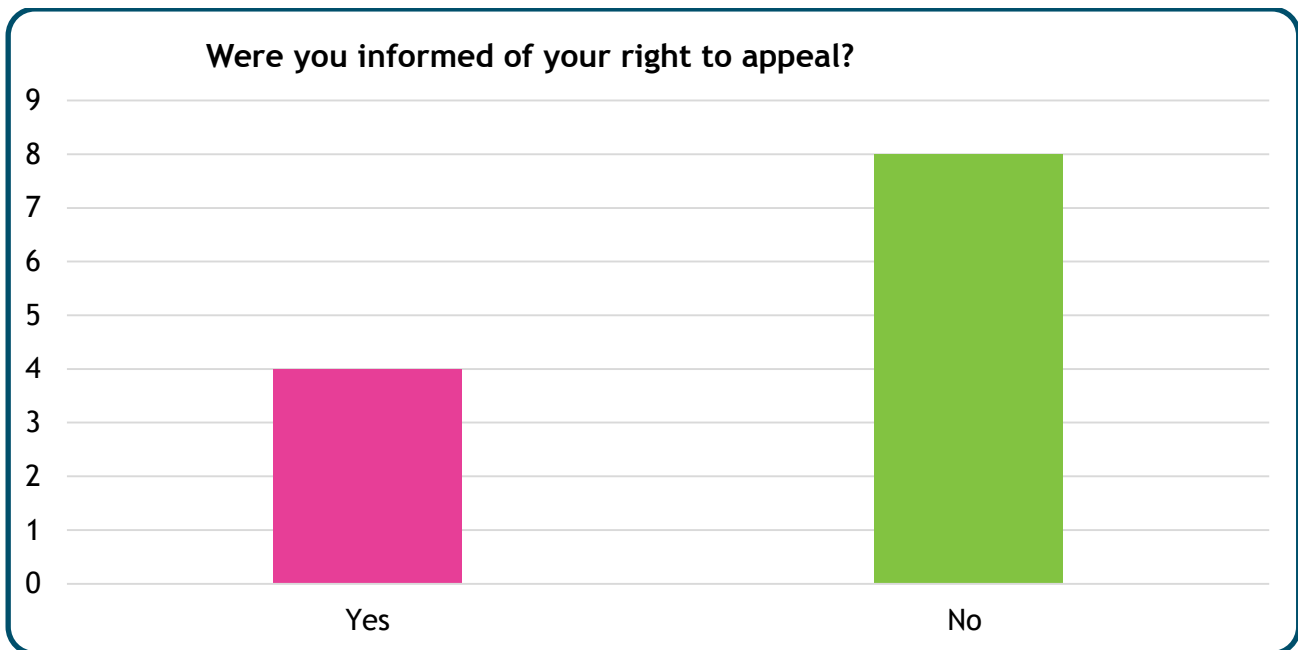
Six respondents said that they waited more than 28 days for a decision and of these, two were at the appeal stage of the process.



Thirteen people answered this question: eight told us that they had been assessed as eligible for CHC funding and five people had not.

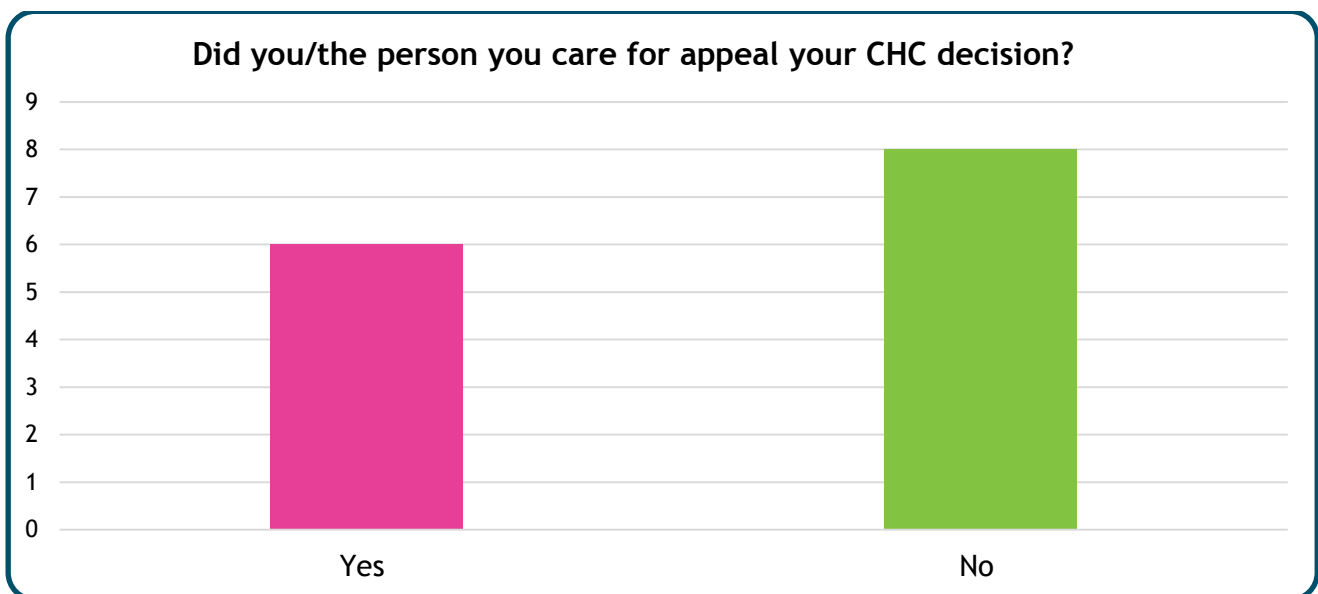
## Appeals

We asked people if they were informed by the CCG of their right to appeal if they were found to be ineligible for CHC funding.



We had 12 respondents to this question: four people told us that they were informed about their right to appeal and eight people told us they were not informed by the CCG of their right to appeal.

We further asked people if they had appealed a negative decision regardless of whether or not they had been informed of their right to appeal.



There were 14 respondents to this question: six people told us that they did appeal an unsuccessful CHC decision and eight people did not.

“More information leaflets and posters carers must be included in all discussions.”

“We waited three and a half years for final decision to be made in my favour and dealt with seven different people in the process. Unfortunately, my mother died three years before the final decision.”

“Even after the appeal was successful it was still an uphill challenge to receive the due payment and it was months before this was refunded.”

## Working with people and their carers

As part of the survey we asked, ‘How do you think the CHC journey could have been improved?’ We received the following responses from people and their carers:

“A follow up appointment to discuss how ‘the journey’ went so that lessons can be learned, from the actual service users who experienced the errors in it!”

“For the whole process to be much quicker and the matter to have been dealt with in a professional and courteous manner instead of feeling that I was being constantly fobbed off.”

“More information leaflets and posters.”

“Carers must be included in all discussions.”

“No questions were asked by CHC after the process was completed to see what my thoughts were.”

“Everyone was passing the buck to different teams, social services, the initial care team brought in, the GP – it was a terrible experience at a time when we needed support.”

“Would just like to say that everyone I have since dealt with at CHC have been brilliant and very understanding.”

# Recommendations

## 1. Information

Lack of suitable and easily accessible information was the consistent message across the whole of the research. It is difficult to know what information, if any, is being provided at the initial checklist stage as the checklist can be completed by a nurse, doctor, other healthcare professional or social worker.

We recommend that good quality information about CHC, the process and timescales, should be given to families at the checklist stage of the journey. This is so people can understand and prepare for the journey ahead. This would also help families to understand the potential financial impact on families and carers as well as helping to manage people's expectations around qualifying for CHC.

- Newcastle Gateshead CCG should develop a communication plan to make professionals aware of the information that currently exists, as well as directing people to its website which displays the NHS England film about CHC at [www.newcastlegatesheadccg.nhs.uk/your-health/continuing-healthcare](http://www.newcastlegatesheadccg.nhs.uk/your-health/continuing-healthcare)

There is also a public information leaflet on the direct.gov website at <https://tinyurl.com/CHCleaflet> and an easy read version at <https://tinyurl.com/CHC-easy-read>

## 2. Hospital discharge and the CHC process

- Newcastle Gateshead CCG to continue to develop consistent training around CHC checklist completion to make practice between Newcastle and Gateshead consistent, ensuring that service users, relatives and carers are fully involved.
- Newcastle Gateshead CCG to work with Newcastle and Gateshead local authorities to agree and implement a consistent approach to dealing with people who are going through the CHC assessment process and are ready for discharge from hospital.

## 3. Improve the assessment process for DST

- Newcastle Gateshead CCG to introduce an independent observer to provide quality assurance at DST meetings; and ensure the national framework is applied consistently by nursing assessors.
- Newcastle Gateshead CCG to provide ongoing training for nursing assessors on the national framework which underpins the DST, including when to use the 12th domain, and to recognise that every CHC assessment should be 'Coughlan compliant'. This means that the assessment must be lawful and adhere to the principles in the Coughlan case.

- Newcastle Gateshead CCG to recognise that the 28-day target may not be achievable in all circumstances if this would mean professionals are not available to contribute (particularly during school holidays) and to ensure that this is discussed and negotiated with the service user, relatives and/or carers.

#### **4. Working with people and their carers**

- Newcastle Gateshead CCG should develop methods to gather feedback regarding people's CHC journey to inform continued improvement.

#### **5. Children in transition into adult services**

- Newcastle and Gateshead local authorities to ensure that children's social workers are aware of their duty to refer children in line with the national framework on CHC and transition. Regular training and audit should take place to ensure this happens.

#### **6. Appeals process**

- Newcastle Gateshead CCG should ensure that people are notified of their right to appeal and directed to support and information regarding this.
- Newcastle Gateshead CCG should gather feedback following the appeals process.

## Responses received

Following the circulation of the draft report, we have received the following responses to the recommendations.

### Children in transition into adult services

- Newcastle and Gateshead local authorities to ensure that children's social workers are aware of their duty to refer children in line with the national framework on CHC and transition. Regular training and audit should take place to ensure this happens.

#### Response

##### Gateshead Council, Service Director

There is work we need to do to make things better for children young people and families and we are determined to get things right. We are working with internal managers to share the findings and will also carry out a full audit on process policies and procedures within the team in April 2018. We are currently discussing how we approach transition in Gateshead.

### Hospital discharge and the CHC process

- Newcastle Gateshead CCG to continue to develop consistent training around CHC checklist completion to make practice between Newcastle and Gateshead consistent, ensuring that service users, relatives and carers are fully involved.
- Newcastle Gateshead CCG to work with both local authorities to agree and implement a consistent approach to dealing with people who are going through the CHC assessment process and are ready for discharge from hospital.

#### Response

##### Newcastle Council, Adult Social Care

We agree that CHC assessments shouldn't in most circumstances happen within the hospital setting but the legislation would guide us to the fact that the interim care package can be funded by the CCG whilst awaiting the assessment. This is a discussion we are beginning to have with the CCG but none of this should impact on the position for the person.

#### Response

##### Gateshead Council, Adult Social Care

We are unaware of delays to hospital discharge waiting for a decision on CHC. Except for one case where the CHC was completed in hospital and this was because the person's needs were very complex.



## Acknowledgements

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- Adult Social Care, Newcastle
- Advocacy Centre North
- Dementia Care
- Disability North
- Gateshead Access Panel
- Gateshead NHS Foundation Trust
- Independent Complaints Advocacy
- Newcastle Council for Voluntary Service
- Newcastle Gateshead CCG
- Newcastle upon Tyne Hospitals NHS Foundation Trust
- Parents in Power
- The Advice Centre
- The Carers Trust

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- Alan Guest
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- Kay Parker
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- Linda Woodcock

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