



NHS Continuing Health Care Report

January 2019/March 2019



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Introduction

Healthwatch Darlington Ltd (HWD) is a strong independent community champion giving local people a voice that improves and enhances health and social care provision on behalf of the people of Darlington. HWD believe that no matter who you are, where you live or what age you are, you do have a voice and you have the right for that voice to be heard.

Our Strategic Duties include:

Information Gathering

- Gathering views, experiences and needs of local people about their health and social care, focusing on those who are under-represented in decision making or face barriers to influencing the system.
- Gathering and monitoring other key information that tells us how the local health and social care system is working for people.

Influencing

- Influencing services and their commissioners to consider and act upon the views, experiences and needs we present.
- Championing the involvement of Darlington residents in the development and evaluation of services.

Informing

- Enabling people to get the most out of the current system by providing information about service provision, the rights people have in relation to their care, and opportunities they have to influence what care looks like.

What is NHS Continuing Health Care?

The National Health Service defines Continuing Health Care (NHS CHC) as:

A package of ongoing care that is arranged and funded solely by NHS where the individual has been found to have a primary health care need as set out in the guidance. Such care is provided to an individual aged 18 or over, to meet needs that have arisen as the result of disability, accident or illness.

Assessment for Continuing Health Care

The assessment process for NHS Continuing Health Care is complex, lengthy and can be both stressful and difficult for patients and carers to understand. The assessment can be carried out at home or in a care setting and the care provided either at home or in a care setting.

There are four possible outcomes from the Continuing Health Care Assessment:

1. Fully funded Continuing Health Care (NHS pays for everything associated with the care of the care of the patient. If the patient is at home the NHS is not responsible for utility bills, mortgage/rent payments associated with the property.)
2. Joint funded care (Social Care and NHS take responsibility for the care of the patient and different % splits are apportioned to each.)
3. Funded Nursing Care
4. No funding responsibility at all for NHS

How it works

The initial stage of the assessment is a Checklist which can be completed by a nurse, doctor, social worker or any health care professional. Each Clinical Commissioning Group decides who can complete the checklist and these people should be trained in its use. This document is used to identify people who may be entitled to Continuing Health Care. If the checklist identifies a need you will then move onto the next stage within the process, but this is not entitlement to CHC.

The next stage of the assessment is a Multi-Disciplinary meeting at which the document called a **Decision Support Tool** will be completed in order to fully assess further the levels of need. Those present should include key professionals from at least two different health and social backgrounds involved with the person's care. Their task is to look at all the evidence about a person's care needs and record the findings using the Decision Support Tool and make a recommendation to the Clinical Commissioning Group. The Clinical Commissioning Group should follow that recommendation in all but exceptional circumstances.

All areas of possible need are covered. These are:

Behaviour	eg aggression, lack of inhibition
Cognition	eg. learning disability
Psychological/emotional needs	eg distressing hallucinations or anxiety
Communication	
Mobility	eg. risk of falls, inability to bear own weight
Nutrition	eg. difficulty in swallowing
Continence	
Skin including tissue viability	eg. pressure ulcers
Breathing	eg. emphysema, chest infection
Drug therapies and medication	eg. help administering medication
Altered states of consciousness	eg. coma
Other significant care needs	

The levels of need in each area are scored as being low, moderate, high, severe or priority and then cross referenced against key indicators: nature, complexity, intensity and unpredictability.

A need should not be discounted because it is being successfully managed. Well managed needs are still needs.

Important Points

- There are very few needs or combination of needs that definitely add up to a **primary care need**.
- There is no diagnosis that makes a person eligible.
- There is no clear definition of where the line is.
- The person being assessed should give consent before the assessment begins. If they lack capacity someone may need to make the decision for them.
- Throughout this process the patient, carer/family should be assisted to understand the process and receive advice to take part in discussions of future care. Information should be distributed and documented within the DST, clinical record.
- It is important that in circumstances where a patient is unable to express an opinion that they have an advocate to speak for them, preferably someone with power of attorney.

Fast-Track

There is also a **Fast-Track** document to trigger a speedy response for a person whose condition is deteriorating rapidly and who are near the end of their life. This document avoids the use of the Decision Support Tool.

Challenging a decision

A decision can be challenged by asking in the first instance for a review. The Clinical Commissioning Group is allowed 3 months to complete this. The next step is to ask NHS England for an Independent Review Panel to investigate the decision. The last step is to go to the Parliamentary and Health Ombudsman. At this point it can be decided to grant Continuing Health Care or the Clinical Commissioning Group may be asked to review again or even to go back to the start of the assessment process. You can find out more by visiting: <https://www.darlingtonccg.nhs.uk/how-we-work/continuing-healthcare/>

‘What’s important to you’ survey? 2018/19

Healthwatch Darlington conducts an annual survey each year across the population of Darlington to find out their views when it comes to health and social care services in the local area. We want to understand which services or elements of health and care they deem priority. We call this survey ‘What is important to you?’

The results from our 2018-2019 survey highlighted **NHS Continuing Health Care** as a one of the priority areas of concern. The results within the survey were presented to our Board of Directors, who then decided on our action plan for the year ahead.



Methodology

Following initial discussion, a small group of our Health Connectors began researching the facts that were available to them through the NHS, Darlington Clinical Commissioning Group and specialist support organisations e.g. Alzheimer's Society. The three documents which lay the foundations for this process were also examined by our Health Connectors in order so that they could gain a deeper understanding of everything involved in the process.

We also examined the recent Care Quality Commission report (Beyond Barriers, how older people move between health and social care in England, July 2018) which had collected qualitative and quantitative data with supporting observations of both good and poor practice. The title Beyond Barriers is well chosen. It is evidenced that barriers certainly do exist, and best practice is beyond what is happening in some areas across the country within our health services.

Despite Continuing Health Care being a possible factor in all these cases used as evidence within this report it is surprising that this sixty nine page report mentions Continuing Health Care only twice. These quotes were as follows; *“In the systems we visited, we saw that people’s discharges were being delayed due to a lack of coordination in conducting assessments. In one system there were over 200 people waiting in hospitals for an initial assessment for continuing health care at the time of our review.” (Page 35) and “In Liverpool, a hospital produced a magazine with comprehensive information on what would happen next after discharge, providing easy to understand information on how to access personal budgets, continuing health care assessments, signposting to other services in the community and other benefits such as carer’s assessments.*

This research gathered was then presented to all of our Health Connector volunteers, several of whom had no prior knowledge of this process for CHC. The assessment process was discussed including the term **primary health care need**.

It was decided that a survey would be designed which would help to gather the views and experiences of individuals living in Darlington.

Subsequently a list of questions was formed as the basis of the questionnaire. The first question was simply - ‘**Are you aware of Continuing Health Care?**’ We wanted to understand how many people were simply just aware of NHS Continuing Health Care. We also wanted to know how people knew about it. We followed with a series of questions to find out peoples’ experiences of the process of accessing this care package. We asked how they felt about the experience as a whole and about the decision that was taken, whether funding was agreed or not.

Our survey was launched on Facebook, Twitter, on the Healthwatch Darlington website and in our own Healthwatch E-Bulletin.

Staff and health connector volunteers also conducted community outreach visits within the community.

These included:

- St Herbert’s D-Caf - (A support café for individuals living with Dementia, their families and carers.)
- Health & Wellbeing Event organised by Darlington College at the Cornmill Centre
- Café JJ - (A community café which is run and delivered by individuals with a learning impairment.)
- Volunteer Fayre at the Dolphin Centre
- Darlington Carers Support Group
- Parkinson’s UK Group
- Hollies Restaurant at Darlington Memorial Hospital

Survey Findings

89 people took part in Healthwatch Darlington's survey. These people were made up of carers, relatives, health professionals or service users.

It's important to note that when we began conducting face to face survey questions with our respondents most of them didn't know what NHS Continuing Health Care was. As we explained to them about the process and what it was for they then realised they had in fact been considered for the funding. 29.31% of our survey respondents had been considered for NHS CHC whilst 17.24% were unsure. This reflects in the results within our findings.

Some individuals only answered certain questions and have skipped questions. The findings below highlight a mixture of quantitative data within graphs and qualitative data which includes real comments direct from the respondent.

1. Are you aware of NHS Continuing Health Care?

89 people responded to question 1 of our survey.

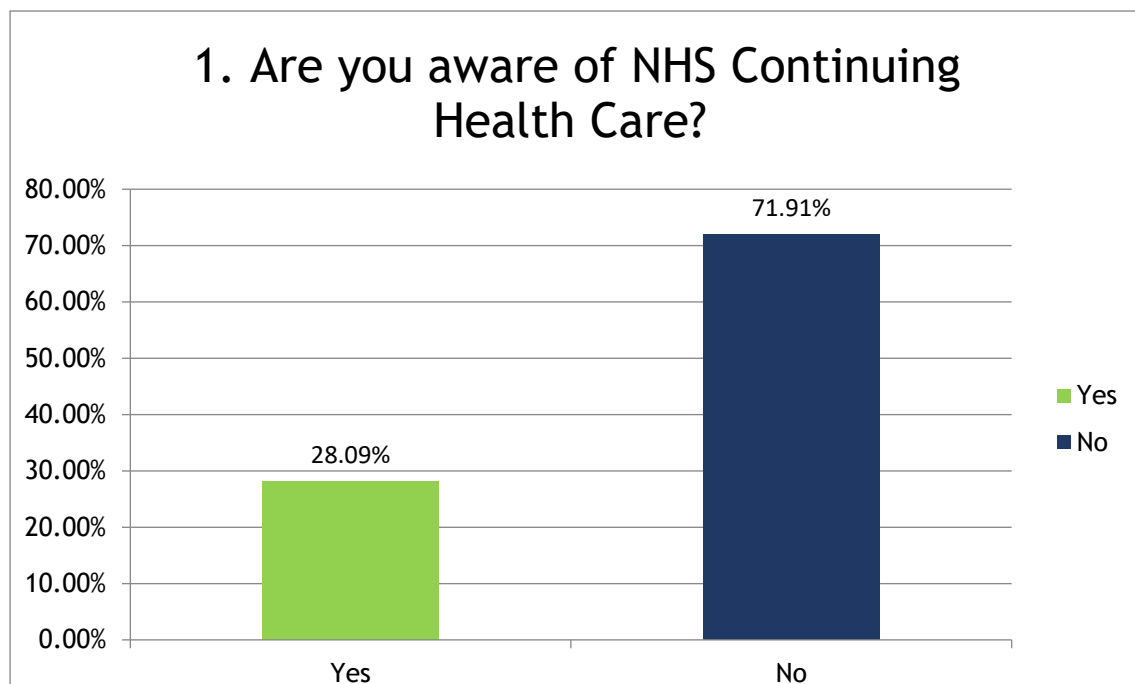


Figure 1 indicates that 71.91% of 89 people did not know about NHS Continuing Health Care.

Figure 1

2. If yes, how did you first find out about it?

29 people who answered question 1 shared their comments below. 12 of these respondents told us they found out about NHS Continuing Health Care because of their professional job role.

- *“Internet”*
- *“Healthwatch”*
- *N/A*
- *“Only because I worked at Age UK.”*
- *“Distressing to appeal.”*
- *“Turn most down and then if you appeal you might get it.”*
- *“Not enough info/and puts people off (information is hard to prove).”*
- *“Adult social care/NHS has too many grey areas.”*
- *“Husband was poorly.”*
- *“Through work”*
- *“Adult Social Care”*
- *“Job role”*
- *“A daily part of working life.”*
- *N/A*
- *“I worked in finance and care residential.”*
- *“NHS lead in local trust”*
- *“Public consultation in a previous survey about a service change”*
- *“Worked in NECS and father just gone through the process.”*
- *“When a family member was transferred from local council direct payments to NHS CHC”*
- *“The Macmillan nurse at JCUH. Told me”*
- *“Through my work”*
- *“When working”*
- *“As an adviser from Citizens Advice Bureau”*
- *“Through my family member”*
- *“When my mum was alive”*
- *“My partner was given NHS CHC when he first became ill.”*
- *“When my dad was ill in Hospital.”*
- *“Relative in Hospital.”*
- *“Through my job.”*

3. Have you or someone you care for ever been considered for NHS Continuing Health Care?

Question 3 was answered by 58 people. Figure 3 indicates that 29.31% of people feel their self or a someone they cared for have been considered for NHS Continuing Care. 53.45% of people told us no. When looking at the reasons behind this mostly they indicated due to a lack of awareness because they didn't need it or because they were not aware it existed. One person did care for someone and one person did look after someone because of their job role. Interestingly 17.24% of people were unsure.

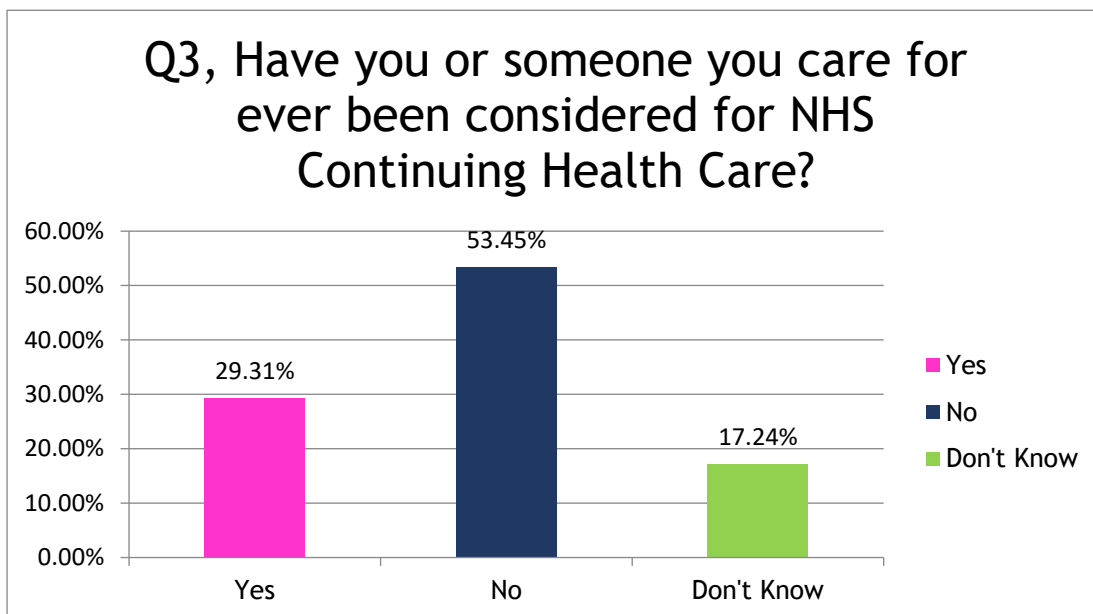


Figure 3



4. Are you aware that the first stage is for an eligibility checklist to be completed for NHS Continuing Health Care?

58 people answered question 4. Figure 4 indicates that 60.34% did not know there was an initial eligibility checklist during the process. Again, it was highlighted that 12.07% were unsure.

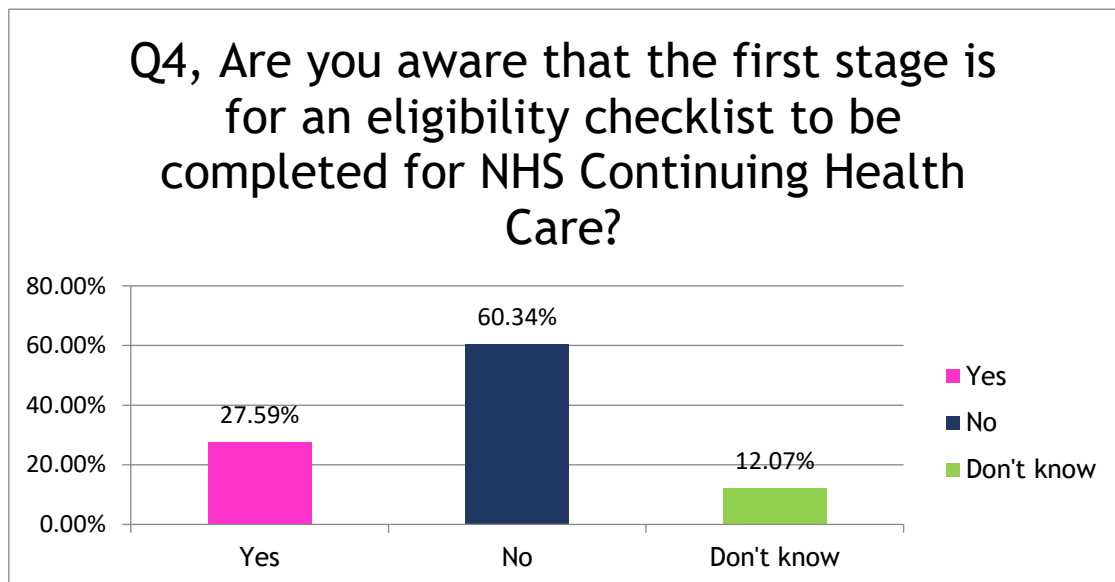


Figure 4

9 respondents left additional comments for this question as indicated below -

- *“To be discussed.”*
- *“Durham County Council, Purchased Care.”*
- *“Yes I think but he couldn’t answer himself. He had Dementia and Parkinson’s so he can answer questions but he doesn’t understand what he is answering.”*
- *“Not aware of this.”*
- *“Not aware of this”*
- *“UAS CHC Lead in previous role.”*
- *“I am unaware of this service.”*
- *“No comment as such as was advised by social worker”*

- *“He was awarded CHC 15 years ago when he first became ill but it was removed almost 10 years later.”*

5. Following on from the eligibility checklist did you or the person you care for proceed to the next stage? (This would involve a Multi-Disciplinary Team (MDT) meeting, completing a form known as a Decision Support Tool (DST)).

47 respondents answered question 5. Figure 6 indicates that 53.19% of people who answered this question did not make it to the next stage for CHC. Interestingly again 29.79% were unsure.

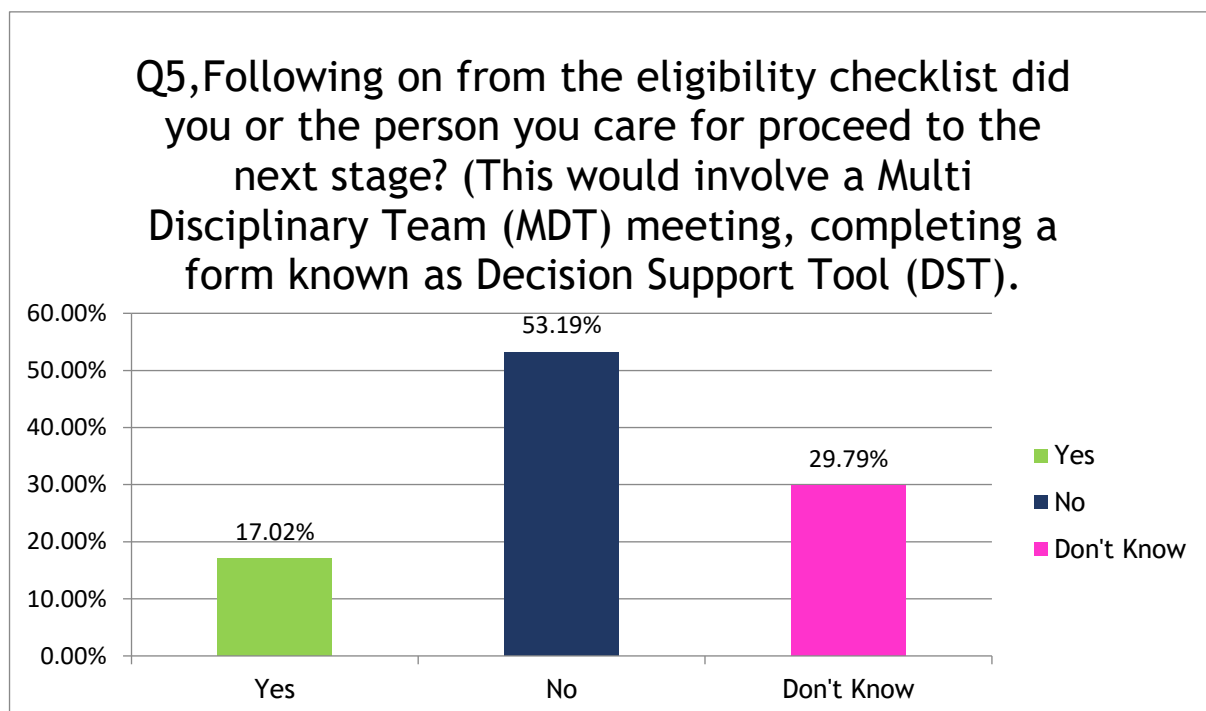


Figure 6

12 respondents left additional comments to this question.

- *“Parkinson’s & Dementia”*
- *“Failure in awareness”*
- *“Failure in awareness”*
- *“Failure in awareness”*

- *“An exhausting procedure where the assessor did not fully take into account how my wife presented.”*
- N/A
- *“Didn't know anything about this while caring for parents with dementia, now caring for brother.”*
- N/A
- *“Discharge from hospital and no longer allowed to go back home.”*
- *“This process was an absolute nightmare as being a lay person with very little understanding of what was going on and very little explanation from the professionals such as the Social Worker and CHC Nurse Assessor.”*
- *“I am seen every 2 months by the Neurosurgeon for a review.”*
- *“It's all a very long process and professionals can change mid process.”*

6. If yes, how did you find your experience when going through the process?

13 respondents answered yes to question 6. We have included these comments from these individuals below. Two individuals shared a positive experience whilst 11 told us the experience was negative.

- *“The person from REACT was appalling and seemed to want to be awkward and unhelpful.”*
- “N/A”
- *“Time wasting. Made up mind before even listening, upsetting, Got it in the end but too late. Should have got it 3-6 months earlier. Person doing checklist can sometimes be more sympathetic but sometimes not.”*
- *“Exhausting, contradictory, not enough prior guidance on what was to come. Shocked at not getting Continuing Healthcare.”*
- *“Process was performed in a timely fashion with full explanation given.”*
- *“The process from sending the checklist to an actual date for a DST is very lengthy sometimes resulting in patients having to move care setting to await DST and this is not always in their best interests.”*

- *“N/A”*
- *“Slow process. discharge team at DMH helped but everything took weeks and there was a lack of coordination when the individuals condition changes. Lack of social worker support. There is a lack of understanding about the emotions involved here or the complexity of some of the information required.”*
- *“OK but dad was in hospital at the time and had many previous admissions, however only the notes from that admission were taken into account and notes were not up to date with everything included.”*
- *“A nightmare as described in comments of previous question.”*
- *“Did not go through the process. No mention was ever made about CHC. It was only later that I found out about it. It appears from other people that this is generally the way. Maybe NHS are trying to avoid paying for care. It also seems that there is a very grey area when it comes to mental health problems about what is a social care need and what is a nursing need.”*
- *“Brilliant”*
- *“Confusing as different professionals have very subjective ideas.”*



7. Were you entitled to NHS Continuing Healthcare?

Question 7 was answered by 30 respondents. Figure 9 indicates that 60% of these individuals were not entitled to NHS CHC.

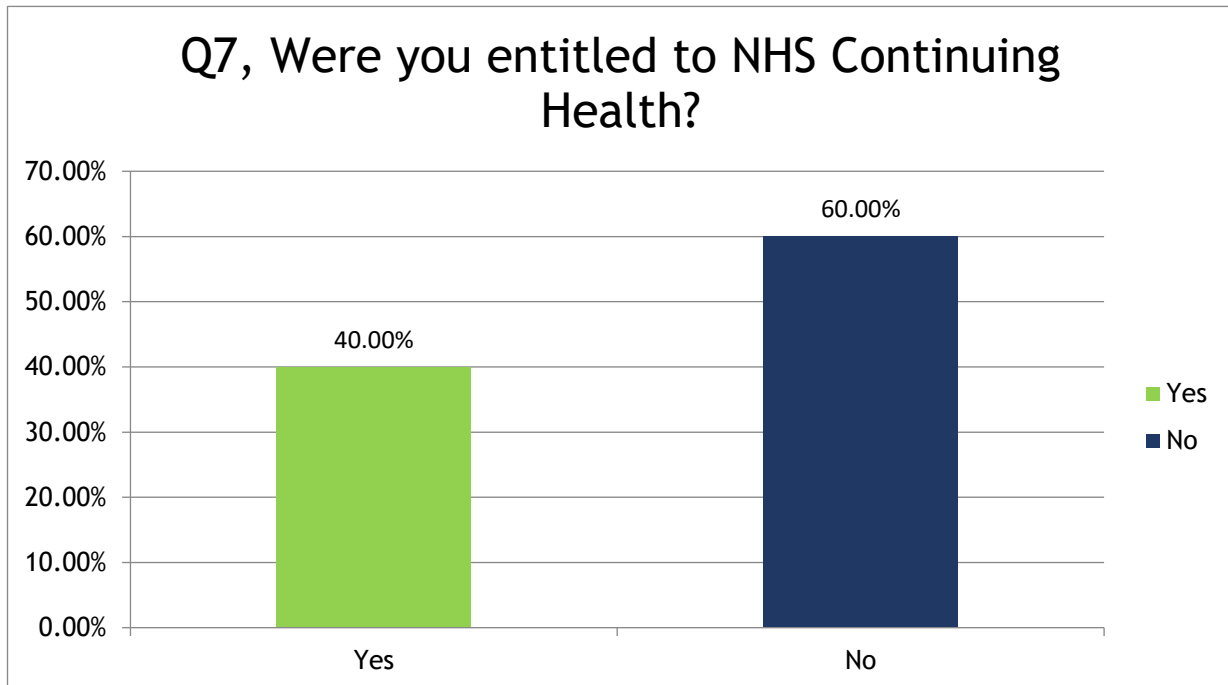


Figure 9

Q8, How did you feel about this decision?

15 people answered this question. Most individuals indicated they were unhappy with their decision. A few people did indicate they were 'Happy' or even 'relieved' with the decision which could indicate a real need for NHS Continuing Health Care.

- *“My relative had Alzheimer's and cancer. I had power of attorney. During her need for care within a care home we were unaware of NHS CHC and we were not offered any help towards care costs. All of her money was sucked up dry.”*
- *“Total lack of help post discharge in timely fashion.”*
- *“Haven't got it. Didn't know about it.”*
- *“Stunned. Not a proper outcome considering my relatives background and how she presented.”*
- *“Relieved.”*

- *“It was a patient I was caring for, not a family member.”*
- *“How would you know if you were entitled.”*
- *“Not affected.”*
- *“Changed on appeal to be eligible, all the information was the same, just provided clarity on a few points. It really does feel like a rationing tool.”*
- *“Received Funded Nursing Care instead.”*
- *“Answered YES as it was family member who was entitled to NHS CHC*
- *My relative applied for CHC when they received a diagnosis of vascular dementia. This was rejected and we ended up solely funding their care until their savings reached the threshold. I feel disappointed that this is the current system we have where people are discriminated against for being diagnosed with a condition like dementia and for saving money throughout their life. Care in the community or at a care home for people with dementia should be solely funded by the NHS. It’s a physical disease damaging the brain therefore it should be classed as a primary health need.”*
- *N/A*
- *“Despite dementia being a medical condition, the needs of people with dementia are often seen as social care rather than healthcare needs. As a result, thousands of people with dementia spend substantial amounts of money on social care they need as a result of their medical condition.”*
- *“Very happy.”*
- *“It was helpful and re assuring.”*
- *“Didn't know about it.”*
- *“Ok but was unaware could have care at home.”*

Healthwatch Darlington Feedback

Healthwatch Darlington have received further feedback directly from an individual aside from the survey results. We have shared an example of this comment below as we felt this was relevant to this report:

A lady telephoned HWD as she was concerned about her parent's decision following on from being assessed for NHS Continuing Health Care. They had been awarded the funding to pay for care however they did not realise that the care provider they could use had to be on an approved NHS register. The parents have been using the same care provider for a number of years and were comfortable with the carers who helped them at home as they knew them. They have been told they can no longer use this care provider and they would need to pick someone else.

Further information

During the final stages of completing this report Healthwatch Darlington's attention was drawn to the recent 'Victoria Derbyshire' programme which featured on the television channel BBC during June 2019. The programme was called 'Our life savings are spent on care that should be free.'

This has highlighted nationally that thousands of families in England claim they are missing out on NHS funding for care that they are legally entitled to. Some families have said they are spending nearly all of their life savings on filling the gaps.

A chairman from the 'Continuing Healthcare Alliance' which is made up of a group of 17 charities and organisations who believe NHS Continuing Health Care' needs to be improved said "*the system is a national scandal.*"

The show featured a number of real-life stories where families share their experience of how they feel let down by the system.

Following on from this show an NHS England spokesperson said "Spending on continuing healthcare is increasing and it is for CCG's to manage assessments based upon demand in their area.

There is still potential however to make the process, more efficient and effective for patients as the majority of people assessed turn out not to be eligible."

Conclusion

When exploring the findings from the NHS Continuing Health Care (NHS CHC) survey we were able to identify that there is a prevalence indicating a lack of awareness when it comes to the general understanding of the process.

Questions three, four and five indicates unawareness amongst our survey respondents. Anyone who was aware of NHS CHC seemed to be a professional from within the health and social care sector. Furthermore, some of the respondents highlighted they only knew about NHS CHC because of their job role. This indicates that general service users and their families don't understand what NHS CHC is or if they have been through the process.

Some of our survey responses indicated that communication during the process was conducted with their loved one, who they felt at the time couldn't answer for themselves. One of these examples was a carer of someone living with Dementia. One individual told us that they had 'power of attorney' but they were still not made aware at any point about NHS CHC. The service users that did take part have indicated they are not being listened to or included within decision making.

Throughout this piece of work the amount of 'don't know' answers being selected within the survey further indicates the general lack of understanding and awareness. This can not only be confusing for families but also distressing during what's already a stressful time in their lives'.

Finally, it was clear when talking to individuals face to face that NHS Continuing Health Care was an emotive subject. Some individuals felt let down by the system and didn't feel a fair decision was made. They went on to tell Healthwatch Darlington that the process was distressing. Anyone who did receive NHS Continuing Health Care felt this was a huge relief.

Recommendations

1. Healthwatch Darlington recommends that Darlington Clinical Commissioning Group review the information available for patients and their families. The information needs to be clear and easy to understand. Signposting and utilising resources from national organisations such as Age UK and Alzheimer's Society could help with this.
2. Healthwatch Darlington recommends that Darlington Clinical Commissioning Group and County Durham and Darlington NHS Foundation Trust should ensure patients can seek further support if anyone is struggling to understand the process. This could be achieved through the appropriate health professionals involved with the process such as the discharge management team, social care workers and community matrons.

Feedback from commissioners and providers

Darlington Clinical Commissioning Group -

“Thank you for sharing the draft Continuing Health Care report with the Clinical Commissioning Group. It is an important topic and we found that the report was interesting and easy to read.

Recommendation 1:

We will review the information we give to those involved using that which is available nationally and signposting to other agencies for guidance. (ie AGE UK)

Recommendation 2:

Again, we will review how and what information is currently available and how it is provided.

Thank you gain for sharing this report with us.”

County Durham & Darlington NHS Foundation Trust -

“CHC/Decision Support Tool is only usually explained to those patients/relatives that meet the initial CHC checklist and are referred for DST. Ward staff complete CHC checklist if the patient has more complex/health needs. Patients and relatives should be invited and involved in the completion of the checklist, however, this may not happen if the patient is unable to cooperate and if relatives are not readily available. The ward staff may complete and refer in the patient's best interest, liaising with family at the next opportunity. Ward staff should inform patient and relatives about the CHC process and that checklist has indicated a referral for CHC consideration.

If a patient meets for CHC consideration (awaits DST), a social worker is allocated and will assess the patient on the ward prior to a DST to expedite discharge, either home with carers or to 24hr care placement.”

Darlington Borough Council -

“There is often a lack of clarity regarding the process for both service users and their carers. Clearer information which is readily available from the Clinical Commissioning Group would be helpful. It is very concerning that the process caused some individuals such a high level of distress.”

Next steps

Healthwatch Darlington appreciates the complexities of NHS Continuing Health Care and we appreciate the responses received from both, Darlington Clinical Commissioning Group, County Durham & Darlington NHS Foundation Trust and Darlington Borough Council. However, we will be monitoring the information & signposting that service users in Darlington receive, when it comes to NHS Continuing Health Care in the future.

Acknowledgments

Healthwatch Darlington would like to thank all of our health connector volunteers for taking the time to help gather views from service users and their families. We would particularly like to acknowledge the hard work that two of our volunteers who have dedicated time to researching and planning for this report.

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