



What you told us about the NHS Continuing Healthcare process

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Report summary

What is this report about?

NHS continuing healthcare (CHC) is a package of care that is arranged and funded by the NHS. Healthwatch Wiltshire has received feedback about NHS continuing healthcare for a number of years. Local people have expressed concerns about their experiences of accessing information, the application process and meeting the eligibility criteria.

What did we do?

In 2019 Bath and North East Somerset, Swindon and Wiltshire (BSW) Clinical Commissioning Group (CCG) asked Healthwatch Wiltshire to work with them to develop a survey to find out people's views and experiences of the CHC application process. The survey was to be distributed to CHC applicants drawn from across BSW. We were due to begin this engagement early in 2020 but it was put on hold until early 2022, when Healthwatch Wiltshire (in collaboration with BSW CCG) surveyed, analysed and evaluated the experience of 20 CHC applicants.

What were the key findings?

- Key information for people applying for CHC is in an NHS leaflet that many people do not receive.
- The majority of applications are made by someone other than the person whose eligibility is assessed.
- People generally prepare very carefully for the assessment, researching eligibility criteria and gathering evidence of need.
- Some applicants find the process complicated and challenging.
- The application process is made easier for people if a social worker assists them, ideally in the initial stage of the application.
- Applicants who meet the eligibility criteria tend to be people who understand the terminology and the role played in the assessment process by the Decision Support Tool.
- Applicants who do not meet the eligibility criteria may complain of not being treated fairly and question the overall process.
- The need for better liaison between CHC teams and care providers, particularly when a change of care setting is required – for example, when a person is moving to a care home.

Conclusions and recommendations

The report draws conclusions from the views and experiences that have been shared with us and makes recommendations based on these. The recommendations make suggestions that aim to improve people's experiences of the continuing healthcare process, based on what they have told us.

Introduction

Healthwatch is your local health and social care champion. We're here to listen to the issues that really matter to people and to hear about your experiences of using local health and social care services.

Healthwatch uses your feedback to better understand the challenges facing the NHS and other care providers and we make sure your experiences improve health and care for everyone – locally and nationally. We can also help you to get the information and advice you need to make the right decisions for you and to get the support you deserve.

[NHS continuing healthcare](#) (CHC) is a package of care that is arranged and funded by the NHS. A team of healthcare professionals assess if an individual is eligible by looking at their needs under the following 12 headings, which are also known as care domains:

- breathing
- nutrition (food and drink)
- continence
- skin (including wounds and ulcers)
- mobility
- communication
- psychological and emotional needs
- cognition (understanding)
- behaviour
- drug therapies and medicine
- altered states of consciousness
- other significant care needs

The person being assessed will be involved in the process and their views will be taken into account. Where appropriate, carers and/or family members may also be consulted.

Healthwatch Wiltshire has received feedback about NHS continuing healthcare for a number of years. Local people have expressed concerns about their experiences of accessing information, the application process and meeting the eligibility criteria. Bath and North East Somerset, Swindon and Wiltshire Clinical Commissioning Group (BSW CCG, now BSW Integrated Care Board) asked us to work with them to develop a survey to find out people's views and experiences of the CHC application process.

We were due to begin this engagement in 2020 but it was put on hold due to the Covid-19 pandemic. As CHC provision is now aligned across the BSW area, it was agreed in early 2022 that this provided a good opportunity to re-start this piece of work jointly with Healthwatch BaNES and Healthwatch Swindon so that patient experience across the BSW region could feed into this process.

What we did

Between March and May 2022 Healthwatch Wiltshire (in collaboration with BSW CCG) evaluated people's experiences of the NHS continuing healthcare process.

This report is based on 20 responses (1 of which was a partial response) to a survey which was sent out with an accompanying letter from CHC to people who had recently applied for NHS continuing healthcare.

87% of the survey respondents were aged 50-90, the majority (82%) female, with an equal percentage (38%) of married and widowed. 17% were single. All respondents were White British.

The majority (63%) of those who responded to the survey were a friend or relative of the person being assessed to see if they were eligible for CHC. Two were patients themselves and 11 were unpaid carers.

Note: The survey did not include a question about repeat applications for CHC, and this was commented on by one of the respondents.

What we found

Information: Nine respondents said they received the NHS England and NHS Improvement (NHSEI) information leaflet in advance of the application and of those who had, four said it did not provide them with the information they needed. So 12 respondents out of 20 had not received relevant information.

Significant preparation is required to apply for CHC, and the majority of respondents made substantial efforts to provide the information to complete the application.

A small number of respondents felt overwhelmed by the complexities of the assessment process. One response indicated that if the applicant's preparation was facilitated by a trained person familiar with the CHC process, this could provide important support with completing the application.

Assessment: CHC involves an assessment process that currently makes a number of demands on applicants, who are required to meet stringent eligibility criteria to qualify for CHC.

The survey responses make clear that those who apply for CHC often find the process a time-consuming and frustrating challenge, and one that may involve more than one application.

Decision Support Tool (DST): 65% of those people who participated in the survey had been assessed as eligible for CHC. Responses indicated that those applicants who were eligible understood the terms used and, importantly, the DST, which is [a national tool to support practitioners](#) in the application of the National Framework for NHS Continuing Healthcare and NHS-Funded Nursing Care 2022 (the National Framework).

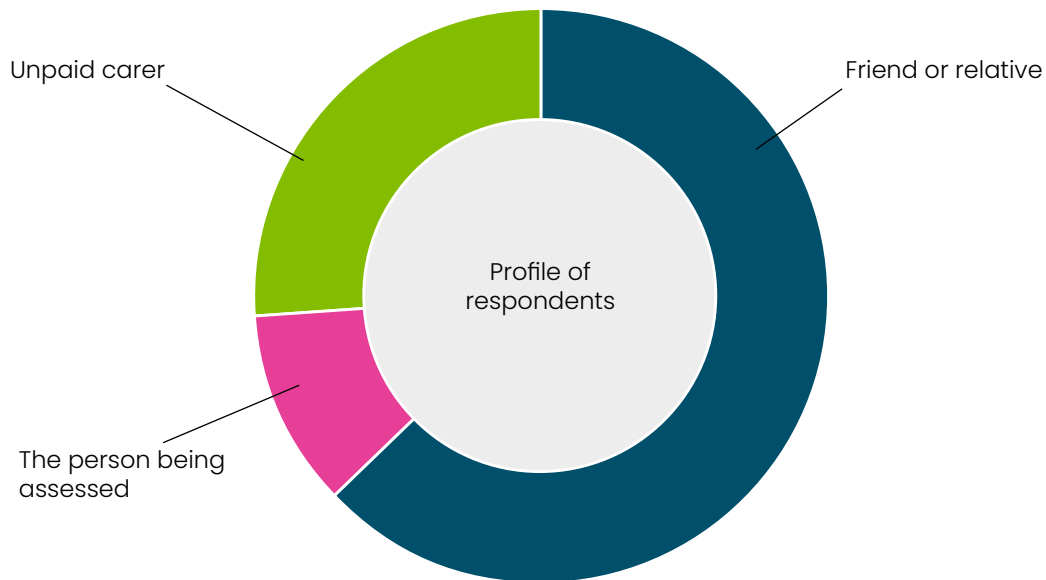
But the scoring system was not always adequately explained, and some respondents said they did not understand the need to appeal as they felt the evidence of the applicant's complex needs was already available.

Eligibility: Given the diligence demonstrated by applicants in their preparations for assessment, often in circumstances of considerable stress and anxiety, some who did not meet the eligibility criteria felt let down and were inclined to question the process itself.

Post-decision care provision: A clear theme that emerged from the survey responses is the need for better liaison between CHC teams and care providers, particularly when a change of care setting is required, as the applicant may need extra help in making the transition.

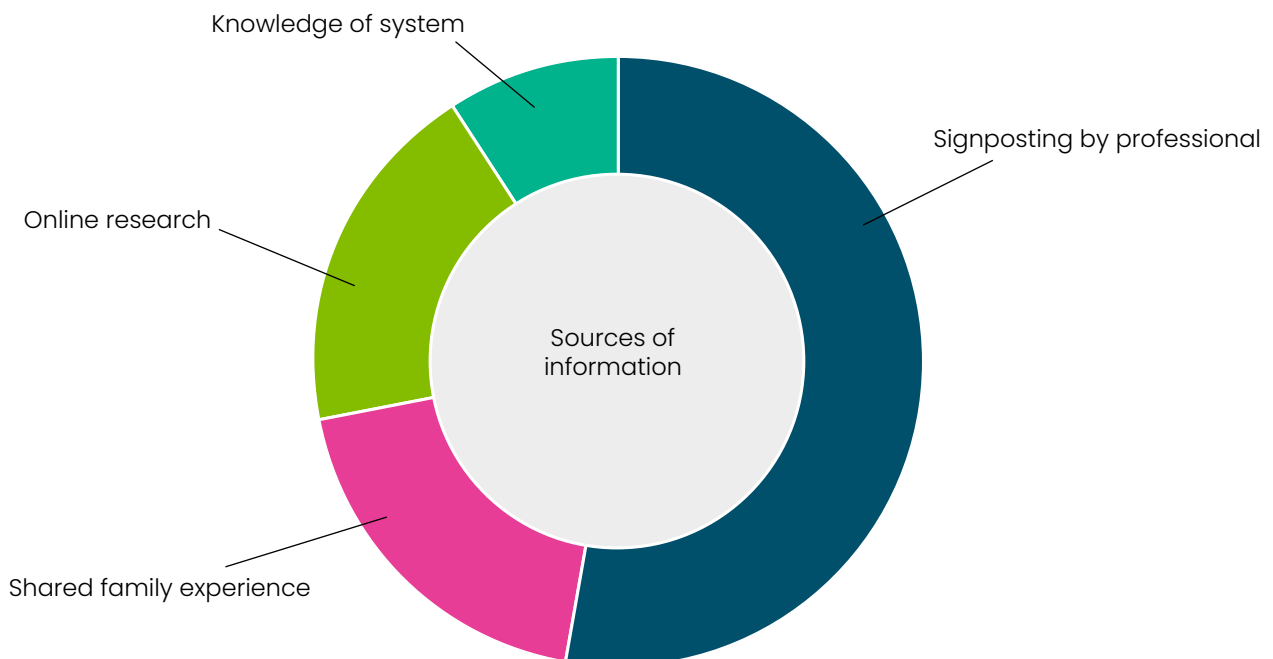
Survey results

1. Are you completing this survey as...?



2. How did you find out about Continuing Healthcare?

Several sources of information, some overlapping, were pinpointed by the survey:



3. Were you provided with a NHSEI information leaflet when the application for CHC was received?

Of 17 replies, just over half (9) said they had received the leaflet.

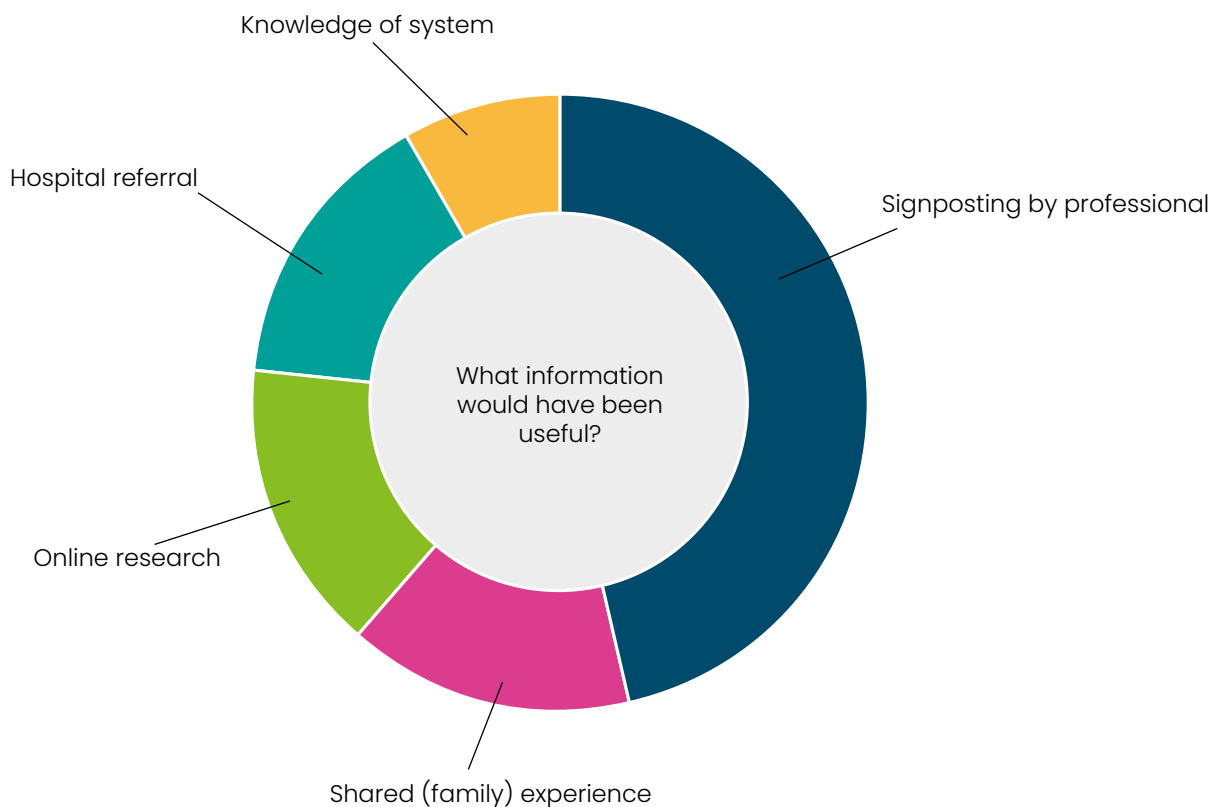
4. Did the leaflet provide the information you required to understand the CHC process and what CHC funding was?

67% of respondents (5) who received the leaflet agreed that it provided the information they needed.

5. Is there any other information that would have been useful?

The answers to this question suggest a level of frustration that resulted from a lack of information available, other than what could be found on the internet. In the experience of one respondent, it was more a lack of consistency in the information available.

- I had to research the internet to get the information I required.
- As a new process for me, it was assumed I understood all the terminology and wording.

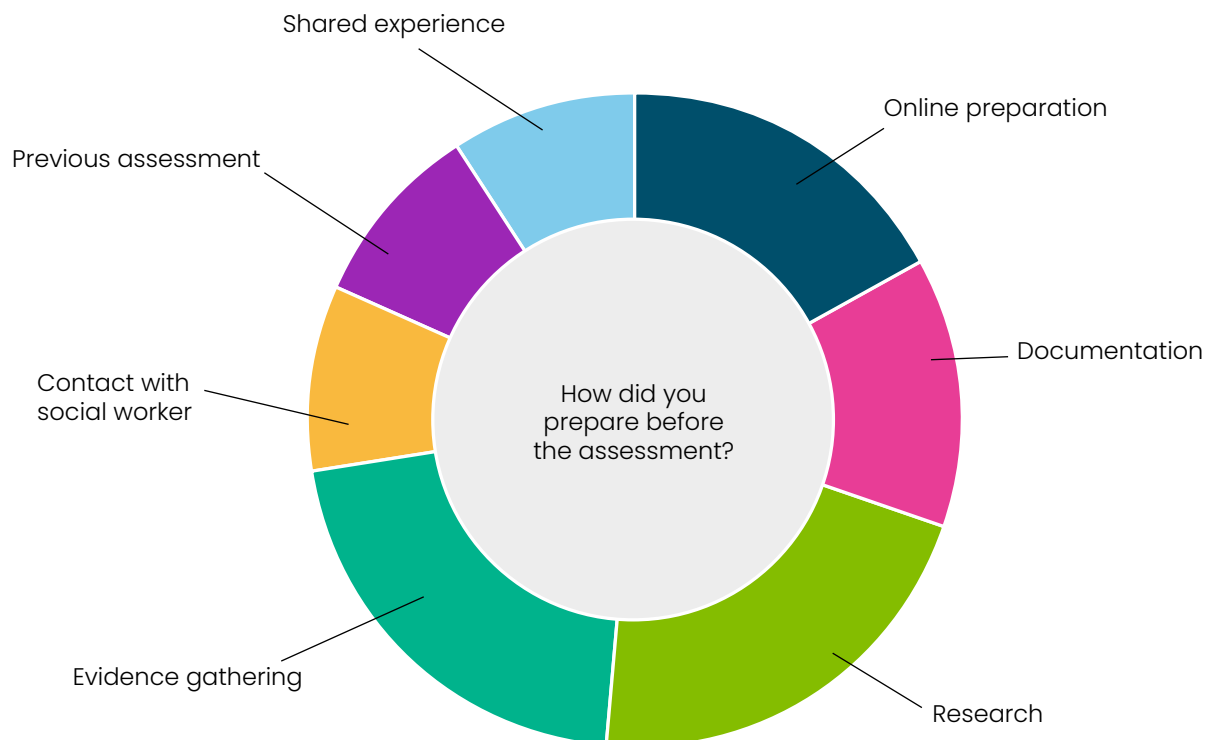


6. Did you do any preparation before your assessment?

(If Yes, please say what you did)

The majority (72%) of respondents prepared for assessment by gathering evidence and mapping needs against the CHC criteria. Those who did prepare demonstrated a wide range of strategies as shown in the quotes below:

- Read the CHC framework and researched.
- Discussed in detail.
- Information and criteria found on the internet.
- Reviewed the decision-making tool, prepared evidence against each of the criteria.
- Looked at CHC criteria and mapped mum's needs and abilities to them.
- I made sure that I had thought about all of the difficulties that I have across all of the areas that I knew I would be asked about. I made sure I had gathered any evidence that I needed to back up what I was telling the team member.
- I read the previous assessment.
- Three hours on phone with social worker.
- We had to download the Age UK Continuing Health Assessment notes and print them off. It took me ages to write notes under each heading using my Smart Box Communication Aid.
- I spent considerable time going through the previous assessment and what had changed. The Neuro nurse and I also spent time going through everything and the home nurse did the same. I had prepared documents and emailed them across including consultants' letters and support documents now available from the MSA Trust [Multiple System Atrophy] who were also supporting us due to the complexity of mum's condition.
- Talked to other parents and looked online.



7. Did the Lead Assessor introduce themselves and explain what would be discussed at the beginning of the assessment?

18 respondents answered yes, one did not answer this question.

8. If you or the person you are responding for has a learning disability or complex needs, do you feel the assessor explained the process and you understood the relevance of care domains and what they mean to you?

65% of respondents answered yes, with 12% disagreeing and 23% saying this question was not applicable. When asked what could have been done better, some respondents had clear issues about how the process was explained and handled.

6 The initial assessment was poorly organised and resulted in my sister-in-law not being accepted (CHC). I requested a reassessment for her and eventually she was granted full CHC. At the time of this incident I was a deputy of the Court of Protection on behalf of my sister in law whose husband died from pancreatic cancer 6 years ago.

9. Did you or your representative understand the terms used in the process and the Decision-Making Tool?

83% of respondents said that they understood the terms used. Those who struggled (17%) with the terms were invited to comment on what would make it easier to understand. Their suggestions included:

Face to face contact would have been far better.

I would like to raise that I am educated to degree level, I have a considerable amount of knowledge of mum's complex condition. I did a lot of research about CHC. I believed I fully understood the process yet when we were told what had happened at this assessment and how the process had not been followed it is very clear that mine and that of my very experienced Neuro nurse are very different to the CHC team. I worry greatly about how others may experience this.

10. To what extent do you agree or disagree with this statement? 'I felt listened to and my comments were included in the assessment document'



11. To what extent do you agree or disagree with this statement? 'My representative felt listened to and their comments were included in the assessment document'?

Responses to this question (answered by 18 respondents) were consistent overall with the responses to the previous question 10, but reflected a slightly higher level of uncertainty.

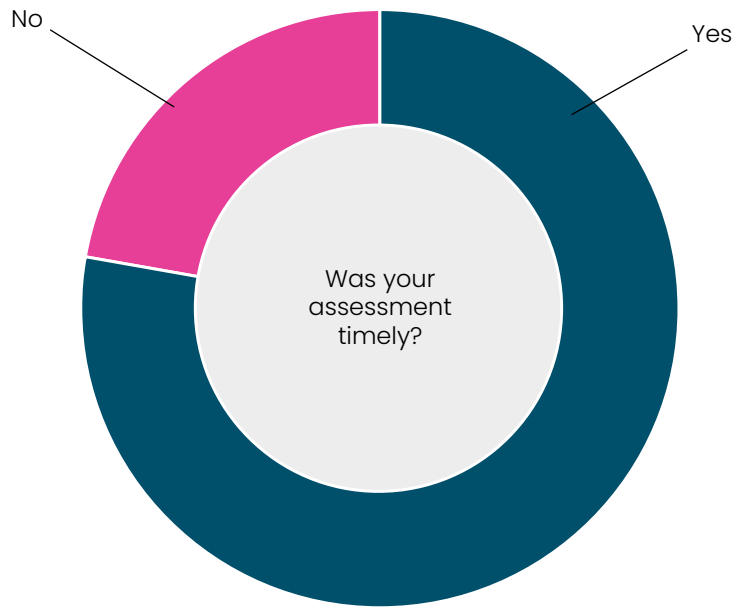


12. Was your assessment timely?

Most respondents (78%) felt their assessment was timely. However, 22% felt it was not timely and experienced delays, or felt that the process was rushed. Comments included:

It could have been done before the Oxfordshire social worker 'closed the case' and before Oxfordshire social services charged my daughter for her care costs at her specialist college.

It took MONTHS to get CHC assessment done, and to get results. Should have been done before mum was discharged from hospital.



13. To what extent do you agree or disagree with this statement? "I was kept informed of the stages of the process and if there was likely to be any delay to the process."

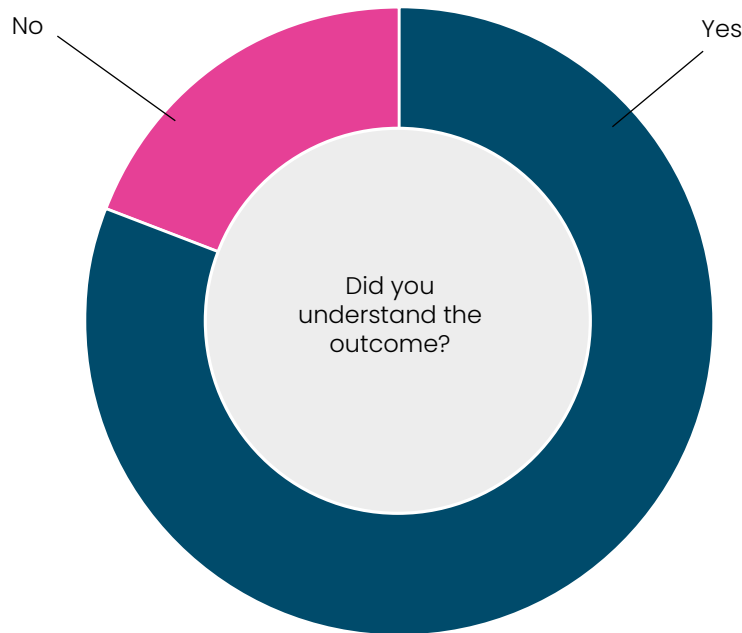
This question elicited a wide range of responses, with just under a quarter (23%) feeling they were not kept informed.



14: What was the outcome of your assessment?

17 people responded and 64% of applications met the eligibility criteria.

15. Did you fully understand the reasons for the eligibility outcome when reading the assessment document and the outcome letter than came with it?



Two respondents gave negative feedback on this.

We were originally passed around the houses once assessment completed, and no one taking responsibility for actioning the assessment asap – delays and denial of providing a package initially, just seemed like unnecessary, impersonal and no apparent lead for decision making at that time.

It came to light that we should have not had a new assessment and that because it had been less than 12 months since the previous decision that only a 'desktop assessment' should have taken place. I can find nothing in any documentation about CHC that explains this! Our Neuro nurse, the nursing home staff and myself had not only spent a whole afternoon on an assessment call but I had spent days preparing documentation and at NO point had this been raised! I had even made contact with social services and they advised that a social worker was being allocated! I have received nothing in writing explaining what had happened and gone wrong, only phone calls. Was this so there was not a paper trail? I even advised that I was finding this extremely distressing.

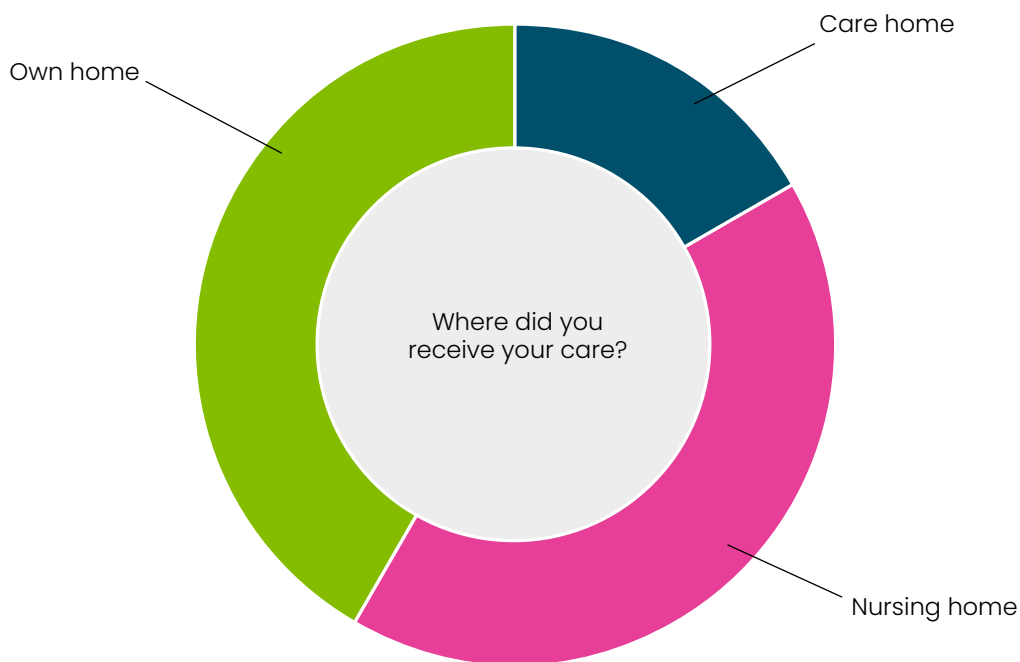
16. If you were eligible, did you receive any care?

92% of these applications resulted in a care package.

17. Did the care you received meet your expectations?

Of the 13 people who were eligible for care, only one responded that they did not receive care that met their expectations. 83% answered that they were satisfied, 17% were only somewhat satisfied.

18. Where did you receive your care?



- “ I was able to use a specialist agency that specifically recruits trains and supports carers solely to look after clients with my particular medical condition. ”
- “ The assessment was clear about the complex needs of my mother’s medical needs. It was less clear on how the care provider was going to deliver that care. ”
- “ [Wey House] has been the best possible home for my sister. ”
- “ Network carers, wonderful and very supportive at all times. ”

19. If you were not eligible, are you considering, or have you asked for an appeal of your eligibility?

Of the seven respondents who were not eligible, four decided to appeal.

20. If you did ask for an appeal, was the outcome of the appeal what you expected?

Two respondents answered this question. One strongly agreed with the outcome of their appeal, the other strongly disagreed.

21. If you appealed the eligibility outcome, was this addressed in a timely manner?

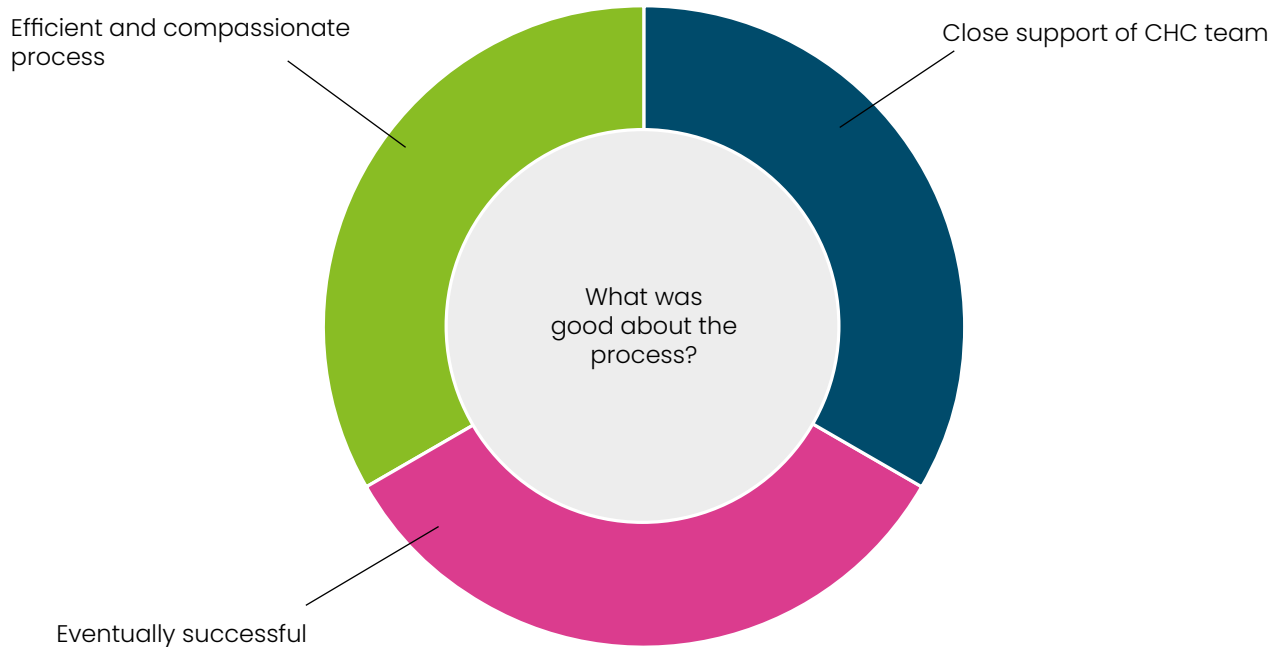
Three people answered this question, two with negative responses, and one to whom the question did not apply.

The whole process was a waste of time, assessor did not investigate or gather all relevant information – nor listen to me or social worker – her reply was constantly 'I do not have the evidence' despite us both telling her. Despite scoring 'severe' in 10 out of 12 categories. The only ones my mother scored OK were 'breathing' and 'conscious' – and these were the only ones that counted apparently. I suspect that between taking a last breath and ink drying on a death certificate someone may possibly qualify!

We were told when it came to light that the correct process had not been followed: we could have further appealed the original 2020 decision. No one seemed to know what they were doing.

22. What was good about the overall process of applying for Continuing Healthcare?

Some people were positive about the process, as illustrated in the chart here.



- It was a fair and thorough hearing and the panel were extremely supportive and empathetic.
- Clear criteria and very empathetic assessor.
- Dealt with by very professional, compassionate team.
- Simple enough to apply for.
- Although it was a fairly long process it was thoroughly assessed and in the case because of the complex needs I believe the right outcome prevailed.

However, some people used this question to reiterate their complaint about the process, as indicated below.

Assessment part fine, but remainder of process laboured and difficult, including recruiting more staff/nurses.

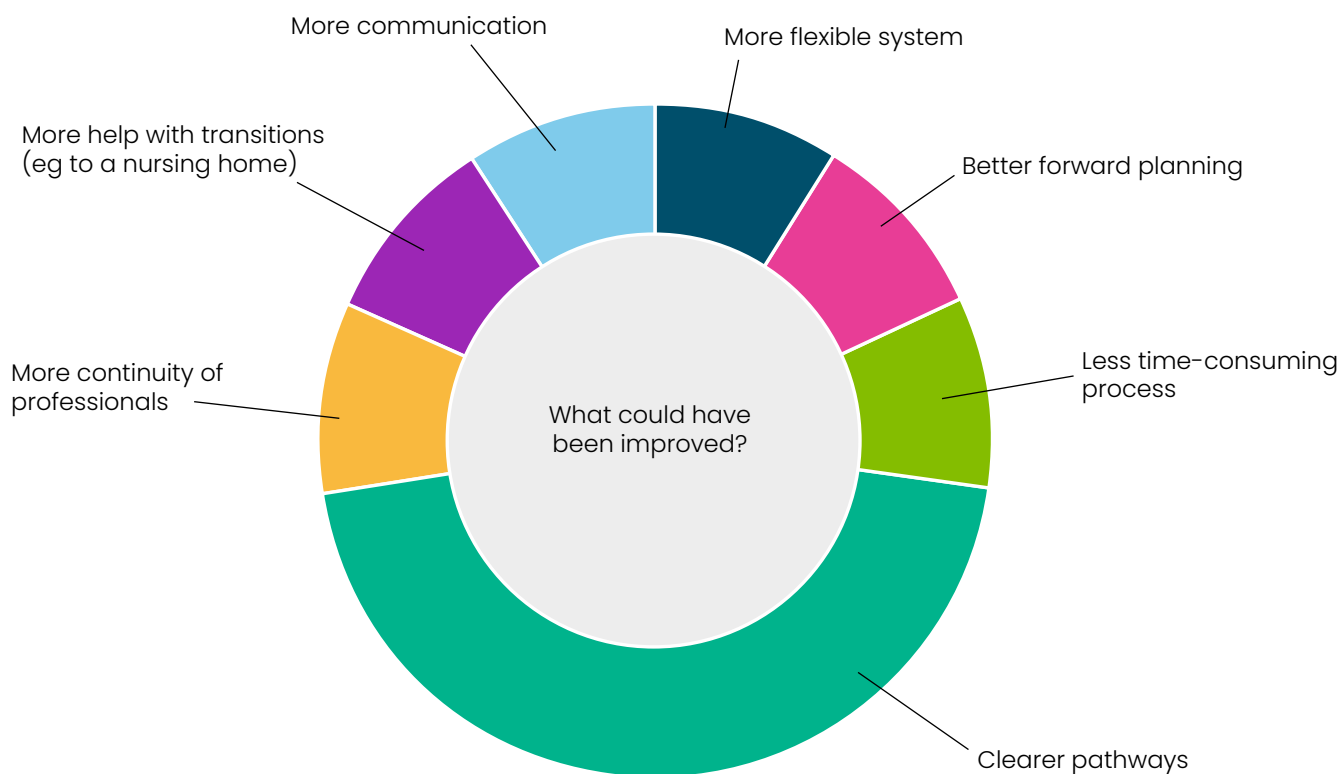
I can't find anything. The whole system is weighted against the applicant. We took external advice, we had been there once before, I am an intelligent person yet the decision makes no sense.

The team did not know the process – this resulted in a considerable amount of time being wasted by many people. The whole process is soul destroying. It 'intends' to support where there is complexity with conditions, yet crossover on the domains are not fully considered.

For rare conditions where there is no 'comparison' or standard pathway, you are set up to fail. In my mum's case the charity supporting us have provided documentation to help with this. I have no idea if this even counts. It was clear from a previous conversation after a split decision (even social services disputed the initial decision in 2020) that unless you are end of life, being tube fed, on a breathing machine then you will fail. There is no consideration of the emotional impact on families. No wonder people give up or don't bother.

23. What did you think could have been improved?

12 people responded to this question.



I don't think an accurate assessment can possibly be made via Teams! You need to see the patient. At the end of the day our loved ones need to be just about taking their last breath before CHC funding will be agreed. The goal posts keep being moved making it nigh on impossible to get any sort of help. Your interpretation of each category makes it impossible to be assessed positively. Complete waste of time.

More help with the transition to the nursing home and expectations made clear to the home. I had to raise difficulties but they were addressed promptly by the CCG.

Better communication; clearer pathways and information about when decisions will be made. Quicker responses/recruitment when know assessments being done. Assessment itself was done by a representative based at Bristol Children's Hospital, and done well. It was when things passed to CHC team that inconsistencies, etc occurred.

Conclusions

The majority of applicants who responded to the survey were satisfied with the process (81%) and accepted the result. The majority of respondents also found the care the applicant subsequently received met their expectations.

It is not clear from the survey results if some respondents described themselves both as a friend or relative of the person and as their unpaid carer. The lived experience of the two people who did their own assessment is understood to be of particular importance, but the observed experience of those who apply on behalf of another person is also important, as this represents a much larger number of interactions with the CHC process.

Overall, the insights gained from the survey – positive and negative – provide a clear understanding of ‘what good looks like’ in respect of CHC.

- Clear criteria and very empathetic assessor.
- Simple enough to apply for.
- Although it was a fairly long process it was thoroughly assessed and in the case because of the complex needs I believe the right outcome prevailed.
- It was a fair and thorough hearing and the panel were extremely supportive and empathetic.
- We were originally passed around the houses once assessment completed, and no one taking responsibility for actioning the assessment asap – delays and denial of providing a package initially, just seemed like unnecessary, impersonal and no apparent lead for decision making at that time.
- I would have liked to have understood the scoring system so that I could be prepared for the likely outcome.
- Better communication; clearer pathways and information about when decisions will be made.
- There is no flex in the system to accommodate rare conditions – it doesn't matter what you do, how much information you provide, how many experts are involved – it has to ‘fit’ within the criteria.

Recommendations

This report makes the following recommendations, based on what people told us:

- Improve the way applicants are prepared for the CHC process by a) making sure they receive the NHSEI information leaflet and b) that they understand the overall process for determining eligibility.
- Ensure all applicants are familiar with key terms, in particular 'primary care need', by providing information in plain English/more easily understood language/appropriate language, particularly if the applicant's first language is not English.
- Manage expectations by ensuring applicants know where they are in the process by making it the responsibility of the Lead Assessor and/or CHC Nurse Coordinator to inform applicants at regular intervals of progress towards a decision.
- Communicate with and manage the expectations of the current or planned care provider, for example, in the situation of an applicant transferring to a new care setting such as a nursing home.
- Ensure the applicant's needs are assessed 'in the round', including the way these needs 'interact' with one another. This is particularly important where an applicant has particular needs that are not easily categorised by the [care domains](#).


Thank you!

Thanks to everyone who shared their experiences with us about the CHC process. And thanks to BSW CCG (now BSW Integrated Care Board) for helping us to distribute our survey.

Response

Kirstie Jackman

Head of Operations and Clinical Quality for Continuing Healthcare (CHC) and Funded Nursing Care (FNC), Bath and North East Somerset, Swindon and Wiltshire Integrated Care Board (BSW ICB)

 I have welcomed the opportunity to work with Healthwatch to gain valuable feedback from our population's experience of the CHC process.

It is positive to see that respondents reported staff were professional, empathetic and supportive but learning will be taken from the comments regarding unclear pathways and managing expectations.

We are currently going through a transformation period with improvements being made to our service delivery model. Our aim is to provide an open, transparent and effective assessment process which the individual and or their representative feels they have been fully involved in and listened to, therefore the feedback we have received from this survey will further inform the changes we make in our processes.

One of the first actions in response to the feedback from the survey will be the development of a BSW ICB CHC Application Process document which will be sent out with the NHSEI information leaflet, this will provide the applicant with the timeline and stages of the CHC application process and will have a Frequently Asked Questions (FAQ) section to provide further information on roles, responsibilities and CHC funding.

We will also continue to seek feedback from everyone who has been through the application process to facilitate ongoing learning and improvements.



Appendix



Survey about the Continuing Healthcare process in Bath and North East Somerset, Swindon and Wiltshire

Introduction

Healthwatch is the independent champion for people using health and care services in Bath and North East Somerset, Swindon and Wiltshire. We listen to what people like about services and what they think could be improved, then share their views with those who have the power to make change happen.

Healthwatch, in collaboration with NHS Bath and North East Somerset, Swindon and Wiltshire Clinical Commissioning Group (BSW CCG), are evaluating peoples experience of the Continuing Healthcare process. We would like to hear your views about this in this survey which is open until 8th May 2022. All responses will be anonymised, and no individuals will be named in the report summarising what people tell us. The report will be used to influence the way the service further develops. By completing this survey, you are agreeing to your response being used for this purpose.

1. Are you completing this survey as?



The person who has been assessed



An unpaid carer of the person



A paid carer of the person



A friend or relative of the person

2. How did you find out about Continuing Healthcare?

3. Were you provided with NHSEI public information leaflet when the application for CHC was received?



Yes



No

4. Did the above leaflet provide the information you required to understand the CHC process and what CHC funding was?



Yes



No

5. Is there any other information that would have been useful?

6. Did you do any preparation before your assessment?



Yes



No

If Yes, please say what you did:

7. Did the Lead Assessor introduce themselves and explain what would be discussed at the beginning of the assessment?



Yes



No

If No, what could have been better explained?

8. If you or the person you are responding for has a learning disability or complex needs, do you feel the assessor explained the process and you understood the relevance of domains and what they mean to you?



Yes



No



Not applicable

If No, how could these be better addressed?

9. Did you or your representative understand the terms used in the process and the Decision-Making Tool?



Yes



No

If no, what would make it easier to understand?

**10. To what extent do you agree or disagree with this statement?
'I felt listened to and my comments were included in the assessment document'**



Strongly Agree



Agree



Neither agree nor disagree



Disagree



Strongly Disagree



Not applicable

**11. To what extent do you agree or disagree with this statement?
'My representative felt listened to and their comments were included in the assessment document'**



Strongly Agree



Agree



Neither agree nor disagree



Disagree



Strongly Disagree



Not applicable

12. Was your assessment timely?



Yes



No

If no, what could have been improved?

13. To what extent do you agree or disagree with this statement?

'I was kept informed of the stages of the process and if there was likely to be any delay to the process'



Strongly Agree



Agree



Neither agree nor disagree



Disagree



Strongly Disagree



Not applicable

14. What was the outcome of your assessment?



Eligible



Not eligible

15. Did you fully understand the reasons for the eligibility outcome when reading the assessment document and the outcome letter than came with it?



Yes



No

If No, how could this be communicated in a better way?

16. If you were eligible, did you receive any care?



Yes



No

17. Did the care you receive meet your expectations?



Yes



Somewhat



No

18. Where did you receive your care?



Care Home



Nursing Home



Own Home

Any further comments about the care that was put in place?

19. If you were not eligible, are you considering, or have you asked for an appeal of your eligibility?



Yes



No



Not applicable

20. If you did ask for an appeal, was the outcome of the appeal what you expected?



Strongly Agree



Agree



Neither agree nor disagree



Disagree



Strongly Disagree



Not applicable

21. If you appealed the eligibility outcome was this addressed in a timely manner?



Yes



No

Is there anything you would like to add?

22. What was good about the overall process of applying for Continuing Healthcare?

23. What did you think could have been improved?

About You

Telling us some information about you (or the person you are completing this form on behalf of) helps us understand how people's experiences may differ depending on personal characteristics. However, you do not have to answer these questions if you do not wish to do so.

24. Please tell us the town or village you live in

25. Please tell us the name of your GP practice

26. Your age



0 - 17



18 - 24



25 - 49



50 - 64



65 - 79



80 - 89



90+



Prefer not to say

27. Your ethnicity



African



Arab



Asian British



Bangladeshi



Black British



Caribbean



Gypsy, Roma, Traveller or Boater



Indian



Pakistani



Chinese or other ethnic background



White British



Any other white background



Any other mixed background



Other



I'd prefer not to say

28. Your gender



Female



Non-binary



Male



Gender Fluid



I'd prefer not to say



Prefer to self-describe:

29. Your marital status



Single



Separated



Married



Widowed



Civil partnership



Cohabiting



Divorced

Please return your completed survey to the address below in the enclosed envelope:

Freepost RTZK-ZZZG-CCBX
Healthwatch Wiltshire
The Independent Living Centre
St. Georges Road
Semington
Trowbridge
BA14 6JQ

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