Findings from engagement with residents of Birch Avenue and Woodland View Care Homes and their relatives.

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Background

Healthwatch Sheffield is the independent consumer watchdog for health and social care in the City. The aim of Healthwatch Sheffield is to seek out the views and experiences of local residents, to help ensure they are involved in the designing, commissioning and monitoring of health and social care services.

Healthwatch Sheffield was approached by Mandy Philbin, Chief Nurse of NHS Sheffield Clinical Commissioning Group (CCG) to undertake independent engagement with residents and their relatives at Birch Avenue and Woodland View dementia care homes in Sheffield.

Over a number of years, concerns have been raised with NHS Sheffield CCG through the campaign group Support 67 about the future of the care homes and whether adequate funding is in place.

The quality of care provided in both homes is rated as 'good' in all domains by the Care Quality Commission[i].

In March 2018, specific concerns were raised about the outcomes of Continuing Health Care (CHC) assessments recently carried out to determine the amount of funding residents would receive towards their care, and the manner in which these were conducted.

NHS Sheffield CCG has reviewed whether the assessments were carried out fairly and consistently according to the national guidance for eligibility[ii]. This continues to be an area of focus at a senior level in the CCG, with discussions taking place at the Governing Body meetings which are held in public.

The Chief Nurse approached Healthwatch Sheffield following the strength of negative feeling that had been shared by relatives about the way in which the assessments were carried out, and in particular, whether people were treated with dignity and respect throughout the process.

We are aware that funding for ongoing care is a sensitive and complex topic, which can affect families and individuals when they are sometimes feeling at their most vulnerable.

The engagement was led by Mark Smith, Volunteer and Engagement Coordinator, with support from Grace Darbyshire, Engagement Officer and Volunteers Liz Bennett and David Boddy.

How did we investigate?

Healthwatch Sheffield arranged two listening sessions at Birch Avenue on 25th April 2018 and 24th May 2018 and one session at Woodland View on 25th May 2018. Healthwatch Sheffield provided posters to advertise the sessions which staff at the homes displayed in advance of the visits.

Healthwatch Sheffield staff and volunteers heard from 20 people during these sessions, including relatives of residents as well as representatives from the Woodland View Dementia Group. These representatives also shared comments from other relatives of residents who were unable to attend the sessions.

In addition, other relatives who were unable to attend the sessions contacted Healthwatch Sheffield directly. We made Sheffield Advocacy Hub aware of the focus of our engagement which led to feedback from an advocate who had represented a resident of one of the care homes at their CHC review.

NHS Sheffield CCG had already made links with Age UK Sheffield and Sheffield Alzheimers Society who support people going through CHC assessments by providing information and advice on the process.

Whilst the focus of this engagement activity was the process of CHC assessments, many people wanted to make positive comments about the good standard of care for residents provided in both homes. It was clear that relatives did not want their family members to move to another care home. A relative whose father is a resident said *"staff at Woodland View are brilliant"* and this was echoed by many others regarding both care homes.

It should be noted that these findings were based on conversations and interviews, not a quantitative analysis.

Key Findings

In this section, some key findings are noted under 6 headings:

1. Assessment and review meetings

1.1 Some relatives said they were given little notice that the CHC assessment would be taking place.

A particular example of this was a relative notified on a Friday that the Decision Support Tool (DST) would take place on the following Tuesday.

The Decision Support Tool is a document where all evidence of a person's care needs is recorded, this information is then used to determine whether they qualify for CHC funding.

1.2 Relatives told us they were not present in all review meetings

A representative from the Woodland View Dementia Group said they were aware of cases in which relatives of residents had not been invited to attend the CHC review.

A relative of a resident of Woodland View told us she felt *"there wasn't sufficient communication to ensure that someone from the family could be there"* for the CHC review.

In another case, the wife of a resident of one of the care homes was receiving treatment for cancer and was not well enough to attend. Letters had been sent to her but she didn't see them due to her illness.

We were also told about one case in which the resident's GP was refused attendance by the CCG.

One relative told us that his wife was not present for her own assessment and assessors didn't actually meet her.

Another relative said there was not enough staff there who knew her family member: *"There were meant to be three people there but sometimes there had to be just two people because of staffing issues".*

2. Care Plans

Feedback from relatives included:

- **In some cases the care plan was factually incorrect**
- **The wrong care plan was reviewed**
- **The care plan was missing**

In one case, a relative told us that, instead of his wife's care plan, another resident's care plan was being reviewed (with the care home nurse and the CHC nurse assessor present). The correct plan wasn't found.

3. Quality of decision making

3.1 Perception that decisions have already been made

The perception that decisions are made before the review itself has taken place was mentioned a number of times. One relative of a resident told us *"you could tell the assessor would decide that mum wouldn't get funded – it seemed obvious she had made up her mind before the review"*.

3. 2 Decision making felt rushed

We were told there were examples where 'quick' reviews were carried out prior to the full CHC review and that the people concerned were not informed this was being done.

3.3 Lack of transparency about eligibility criteria and the wider process

A relative of a resident of Birch Avenue told us he received a copy of his mum's assessment but questioned the wording used to describe her needs. He said *"As a relative you don't understand the implications of what 'severe' means"*.

Needs are assessed based on 12 'domains' (e.g. nutrition, behaviour, skin, mobility) and each domain is assessed based on four to six levels of need, from 'no need' to 'priority'.

A daughter of a resident said she was pleased that her mum, who was sedentary, had never had a bed sore. She felt that this indicated how good the care was at the home, not that her mum's needs were 'low' on the skin domain. She questioned whether the only way to have her needs recognised would be if she had open sores that needed to be dressed regularly.

A relative of a resident said they thought that *"If you don't have behaviour on as 'high', it doesn't matter what you get on others".*

This confusion was evident in many conversations, with a variety of views about the importance of one domain over another and how they relate to one another, for example, that if cognition is 'severe' then psychological and emotional needs are always judged to be 'low'.

A relative of a resident described the assessment: *"Throughout the DST (the assessor) refused permission to go back to a different domain but kept referring to other domains".*

This confusion led to a sense that the assessors were not being open and this was made worse by a lack of clarity about the relationship between the lead nurse and the CHC assessors. Some people said the lead nurse attended assessments and also met privately with the assessors after the assessments - this upset relatives.

Several relatives referred to a mistrust in the dispute resolution process and perhaps a lack of transparency has contributed to this.

In two cases we were told that the social worker had disagreed with the review decision to lose funding and thought the relative should be funded. The Quality Assurance Committee of the CCG does not see or know the patient. A senior social worker sits on this committee and it is seen as unfair that they can override the view of the social worker who has actually met the person.

3. 4 Money driven decisions

One relative said that they were called in (by the lead nurse and the assessors) after the

assessment and told that their withdrawal of funding was because of CCG financial difficulties.

4. Lack of accessible information

Relatives said they were not given information and therefore were unaware of their rights. Some people who had seen the national framework document found it too long at 167 pages. It should also be noted that this document is not aimed at the public and that there are other sources of information available for individuals and their families.

One advocate who was working on behalf of a resident told us that they were unable to access all the paper work they needed in order to lodge an appeal against a CHC review decision: *"The CCG wouldn't let me see the 2014 DST notes because they said I wasn't there"*.

Another relative of a resident said he didn't understand all the questions and felt they were not explained to him and he wasn't given any literature. He was invited to attend the assessment which he went to - he referred to the process as 'cruel'.

5. Expectations

Overall, relatives had taken away the message (from a meeting in 2012, chaired by the Chair of NHS Sheffield CCG) that the care homes were a "home for life" and they were shocked that funding might be withdrawn, meaning that their relatives would have to leave. We were told there were eight empty rooms at Birch Avenue and further empty beds at Woodland View and this frustrated relatives.

6. Impact of the CHC reviews and decisions

There was a general perception that Sheffield CCG did not understand the personal impact on residents and their families of the CHC assessments.

Several people commented that where individuals are obviously entitled to CHC (their needs hadn't changed) it was uncaring to put them and their families through the stress of a full assessment.

An advocate for a resident said: *"There is no regard for the clients and what moving them would mean to them".*

A relative of a resident told us how the assessment affected her: *"Its all very worrying and distressing…I now keep a list of all the times when he (husband) has been aggressive towards others".*

The husband of a resident said *"we feel we are being threatened".*

Recommendations

We recognise that there seems to have been a breakdown of trust between NHS Sheffield CCG and many relatives of residents of Woodland View and Birch Avenue Care homes, and this needs to be addressed as a priority.

Inviting Healthwatch Sheffield to independently listen to and summarise the views and experiences of relatives of residents in both homes is a positive step towards open dialogue.

We recommend that NHS Sheffield CCG:

1. Reflect on the views and experiences described in this report with members of the CHC team and consider how the approach to CHC assessments can be made more person centred. The Core Principles of the national framework describe what it means to be person centred in this context.

2. Consider making improvements based on (page 17) paragraph 44 of the national framework: "*Assessments of eligibility for NHS continuing healthcare and NHS-funded nursing care should be organised so that the individual being assessed and their representative understand the process, and receive advice and information that will maximise their ability to participate in informed decision-making about their future care. Decisions and rationales that relate to eligibility should be transparent from the outset for individuals, carers, family and staff alike".*

3. Improve the range and accessibility of information made available to individuals and their families, including the following: Department of Health Public Information Leaflet, Age UK Factsheet and NHS England Continuing Health Care film.

4. Demonstrate greater recognition of the stress experienced by families and individuals during CHC assessments, by showing compassion and understanding.

   Local adherence to practice Guidance(page 53) note 4 of the national framework should be reviewed in light of the findings of this investigation.

   "Despite professional intentions to treat individuals with dignity and respect, the perception of individuals can be that this is not always the case. It is important for practitioners to put themselves in the position of the individual by asking questions like:
   'How would I feel if this was happening to me?'
   'Have I really tried to understand what this person wants, what is important to them now and for the future?'"

5. Liaise with Healtwatch Sheffield, Sheffield Advocacy Hub and other keys partners about how to improve the CHC process.

NHS Sheffield CCG response

We'd like to thank Healthwatch Sheffield for carrying out this invaluable piece of work. We appreciate your staff talking to relatives and representatives to hear about their concerns and issues. This report has helped us focus on where we need to improve.

We are sincerely committed to not only listening to residents but also improving CHC processes, how we communicate with residents and their families , and the care delivered. We understand that CHC assessments and reviews can cause worry and upset, and we want to avoid this.

In light of the concerns and Healthwatch's recommendations, the CCG has developed an action plan. This plan will be presented to a governing body committee in September to ensure governing body members, senior staff, and our partners are able to scrutinise and shape the plan before being finalised.

Our plan covers all of the recommendations above and we're pleased to say that many of the actions have already started.

1. We will change the culture of the CCG by focusing on training for staff (jointly with Sheffield City Council on communication skills for nursing staff and social workers), and putting patient experience on the agendas of all CHC team meetings.
   At the heart of this, is promoting our For Pete's Sake campaign, where we ask staff to think of at least one change they can make which will make a difference to patients' lives.
2. We will have a big focus on improving how we communicate with patients and relatives on the process, eligibility criteria and how people can be supported. One of these actions is to involve relatives in a review of existing communication materials to make sure they are right. We will also publish this on our website.
   Part of this work will involve working more closely with the council, so patients and relatives receive a seamless service.
3. As above and we will also work with voluntary sector in doing this.
4. Showing compassion and understanding will be a big part of the communication training for staff, as will the For Pete's Sake campaign. We will also work with the advocacy hub, Age UK and Alzheimer's and signpost these invaluable services to relatives.
   We have also carried out complaints training with senior staff to ensure responses to our complaints are more empathetic.
5. We are absolutely committed to doing this. We want to continue and build on the partnership working with Healthwatch and the voluntary sector. We are also working closely with the council to improve how we work together and improve the experiences of patients and their families.

Finally, on behalf of the governing body we'd like to again thank Healthwatch Sheffield for their hard work in producing the report and the relatives in giving their honest feedback.

Next steps

Healthwatch Sheffield will take forward a number of actions in light of the findings of this engagement:

- Initiate a meeting between Sheffield Advocacy Hub and NHS Sheffield CCG - for information sharing and learning opportunities.

- Engage local Voluntary and Community Faith (VCF) groups who support people through the CHC process by devoting a future VCF Health and Wellbeing Forum meeting to the topic.

- Include CHC as a priority area in the Healthwatch Sheffield Strategy 2018-2020 to ensure a wider range of views and experiences are taken into account.

- Collaborate with NHS Sheffield CCG and groups representing patient and carer voices on further engagement activities to capture the experiences and views of local people. And furthermore to use this intelligence to make recommendations which will influence decision making.

We would like to thank NHS Sheffield CCG, and in particular, Chief Nurse, Mandy Philbin for instigating this investigation. We also thank the staff, residents and relatives of Birch Avenue and Woodland View Care Home for welcoming us and sharing their experiences. And finally thanks to our volunteers, David Boddy and Liz Bennett for their openness and sensitivity.

[i] Care Quality Commission inspection findings for Birch Avenue, Report published, 29 June 2018: https://www.cqc.org.uk/location/1-117578601 and for Woodland View, Report published 22 April 2017: https://www.cqc.org.uk/location/TAH95

[ii] National framework for NHS continuing healthcare and NHS-funded nursing care, Published 28 November 2012 Last updated 11 May 2018, https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care