Findings from a focus group about Continuing Health Care assessments on 4th December 2018.

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.

The equity and experiences of Continuing Health Care (CHC) assessments is a priority area for Healthwatch Sheffield in 2018/19. This means that it's one of the main issues that we will focus on to help make health and social care services work better.

Whilst the people's experiences of the CHC assessment process can be confusing, frustrating and stressful, a 'service development project' has been initiated by NHS Sheffield Clinical Commissioning Group (CCG) and Sheffield City Council (SCC).

The CHC Service Development Project is a collaborative effort between Sheffield CCG and Sheffield City Council to design a single health and social care CHC assessment process with the individual and their family at the centre of all decision making.

The project team recognise that public involvement is required to better understand:

- how the current approach impacts on people's lives,
- how people who have been through the process think the approach could be improved,
- the role of the voluntary and community sector in supporting people through the CHC process,
- how people would like to be involved with monitoring the quality of CHC assessments in the future,
- what type of information people would like to receive and how this should be communicated.

Healthwatch Sheffield provided initial support to the project team by:

- sharing existing intelligence from local citizens and members of relevant voluntary and community groups,
- making connections between the Sheffield Advocacy Hub and NHS Sheffield CCG.

Further to this, a series of engagement activities were planned:

- two listening sessions at Birch Avenue and Woodland View dementia care homes,
- a dedicated Voluntary, Community and Faith Sector Health & Wellbeing Forum,
- a small focus group for people who have experienced the CHC assessment process themselves or have supported someone who has been through the process.

After the first two events, the CCG and Council hosted a workshop to jointly develop a core set of operating values and behaviours for the health and social care workforce. This was informed by the outcomes of the earlier events, and some service users and carers were invited to attend and share their views and experiences with the wider workforce.

Format

An information sheet was provided to all participants (appendix 1).

The focus group was split into two parts, with the first part focused on gathering people's views, with a visual representation of good and bad experiences at each point of the process.

Participants were invited to indicate if their experience was as someone who had experienced their own CHC assessment or as someone who has supported another person who has been through the process.

Participants helped to name the key parts of the process and add a coloured spot under each heading to show whether their overall experience of this part of the process was good or bad. Participants wrote their own comments or were supported to do this. These comments have been recorded directly in the findings (pages 5-8) along with a summary written by a facilitator.

The facilitator asked participants to explain what was good or bad and to expand on the context and impact of their experience. Participants also discussed what could have been different to make their experience better.

After a comfort break, the second part focused on how the voices of service users and their carers/families can be heard during the assessment process and how they can be kept up to date. People were invited to fill in a 'CHC News' template (pages 9-13).

Views were sought on:

- at which point/s feedback should be sought,
- how the information should be shared,
- how people want to be kept informed.

People were invited to fill in 'CHC News' template, then share their views and discuss each of the four areas.

Participants were informed that the findings would be shared with everyone in attendance and that they would have chance to check any inaccuracies.

The CCG Project Lead expressed thanks and explained that participants input would be sought in the future and that they would be updated on the difference sharing their experiences makes.

Attendance and limitations

Seven people attended the focus group, four women and three men. Two people who had experienced their own CHC assessment, and five people who had supported another person who had been through the process.

The focus group approach can exclude people who are housebound and with limited mobility/lack of support to leave the home. People who were unable to attend were invited to comment by phone, email or post.

Findings

People recorded their own responses and these have been collated in the template on page 4. Where events were neutral or there were equal positive and negative experiences, some participants chose to use red *and* green stickers. For the purposes of this report, these experiences have been shown in orange.

Some information has been changed to protect participants' anonymity. This is shown using square brackets.

Recurrent themes from the discussions

Communication

There can be multiple staff involved in a single assessment and this can lead to inconsistencies. For example, in communication styles, and in the understanding the staff have of the case. It can take a long time for new workers to really understand a person's needs.

People described big differences in the way that professionals interact with individuals and with paid and unpaid carers.

Sometimes key pieces of information were not shared. For example, what decision had been made and what specific parts of the process involved, especially 'dispute'. Two participants said they hadn't been given contact details for follow up.

One participant said that communication was so poor that the only way to ensure action was to make a complaint, even though the problem had begun as a small issue that should have been resolved fairly easily.

Trust and relationships

Paid and unpaid carers both expressed frustration at both the pressure put on them during the assessment process, and that they weren't always listened to. One paid carer said they felt 'belittled' and that their knowledge was challenged, when actually they considered themselves to be an expert in the individual's needs.

Participants said they wanted to be treated with respect. Punctuality, politeness and preparedness all make a difference. The concept of acting collaboratively, with the ‘team’ (individuals and carers) being accepted by health and social care professionals as ‘colleagues’, was important to participants.

When the assessor was perceived as skilled and supportive this led to greater trust in the process. The most positive experiences involved high levels of trust – the staff were ‘warm and friendly’, ‘skilled and patient’ and ‘took time to listen, then whatever the outcome, at least it’s based on the right information.’

Trust in the process can be very difficult to achieve when the process itself can be confusing, for example, the evidence that will be accepted is not always clear and the criteria appears to be open to interpretation. One participant with extensive experience said that in their opinion the tool is ‘inaccurate’ with ‘narrow criteria that does not reflect the intricacy of need.’

Evidence

Some participants described feeling confused about what evidence would be accepted and that some key sources of evidence were not included. For example, the experience of staff at a care company who were familiar with the level of complexity of needs.

One participant explained that it was difficult to describe the full extent of their family member’s needs in front of them without causing distress and this affected the evidence they were able to present.

There were also concerns that if a person’s care is good, their needs may appear to be reduced, but that this is actually an indication that their level of support is at the right level.

Improving experience and monitoring quality

Participants were clear that asking about the experience at the end of the process would be ‘too late’ and that people should be offered the opportunity to ask questions and give feedback after the first 1:1 – to prevent ‘niggles’ from escalating.

Good quality information about what will happen should be given at the beginning of the process, with contact details. People would also like to have tips and advice provided, for example ‘if you want to be well prepared, do this’ and perhaps to read the stories of other people who have been through the assessment process.

There was also agreement that an initial phone call from the assessing nurse, prior to the assessment would help build rapport and trust as well as providing an opportunity to share confidential/sensitive information or concerns, and to ask questions.

There were some concerns expressed about whether a questionnaire would be the right format and whether people would be concerned about reprisals if they shared negative comments. People who had been through the process felt very aware of the power held by CHC assessors.

However, participants did recognise the value of a questionnaire in the right format, used at the right time and with the results being received by a third party, such as the patient experience team, rather than the CHC team.

People were keen that the information captured, and the difference it makes, would be shared with service users and relatives.

Information sharing/keeping up to date

Participants welcomed the idea of better information sharing in the form of a newsletter. In addition to the views captured on the newsletter templates (pages 9-13), topics for inclusion were: the role of independent advocacy, how paid and unpaid carers can be involved in the process, and sources of information and support, particularly for people without a support network.

Tell us about your experience of the Continuing Heath Care process

- You can use the **green** dots to show whether the overall experience at a certain stage was **positive** and **red** dots to show where in the process you were **not satisfied** with the overall experience.
- If you have not been through a particular stage/s then please leave the relevant box or boxes **empty.**
- You can use the pens to make more detailed comments (e.g. reasons for your rating and how you felt.

	Health/nursing needs identified	**Initial assessment- the 'Checklist'**	**Full assessment- 'Decision Support Tool' (DST)**	**Told funding decision**	**Dispute resolution or appeal**	**Experience of care**	**Annual Review**
Person 1 Someone in receipt of/being assessed for CHC funding	Social care led		Length of time (2 nurses) after I was off ill. 2nd did 3 visits. Disparity in nurses presentation.	Unfair split health low. Social care have to pick up rest.	Unclear whether information on process to dispute should only expected a complaint.	If been in disagreement with decision and not rectified would be uncomfortable with process & practice.	Generally yearly (timely)
Person 2 Someone in receipt of/being assessed for CHC funding	People were interested and looked for reasons to do it and a positive outcome. It was a friendly experience.	People involved wanted us to be successful and help me achieve my aims. It made me feel able to relax and say what I needed to say.	We were able to bring out everything we were facing and encouraged to bring out all the areas we needed help.	The funding makes a tremendous difference. It allows me to do some things for myself. I felt tremendous, of the highlight days of the last few years, this was one of them.		I've got people working with me who are interested in me. They have got the time to work with me because of the funding. Everyone I've come across has wanted to help me.	

Person 3 Carer/family member of someone in receipt of/being assessed for CHC funding			Felt 'belittled' as a PA. Felt as though our knowledge of [individual] nad [their] needs wasn't listened to – sometimes even actively challenged.	Confusion around health and social split of package. Had part of payment changed after sign off which we had to fight to have returned to normal. Full package agreed after five years, even if there was a dispute over the split.	Disputing the health/social split proved difficult due to unclear framework and general communication being poor. Now resolved although ongoing issues with [individual's] DP.	[Individual] has what [they] need in the form of the package to have 24/7 care. The process was stressful and felt like a fight as opposed to a collaboration.	
Person 4 Carer/family member of someone in receipt of/being assessed for CHC funding			Initial visit for DST went well although CHC nurse went on leave before decision was made. When chased up and next CHC nurse slowed things down and really bad values and behaviours from nurse.	Pleased with outcome that we finally got funding we were fighting for, however still felt it was an unfair split between health and social care different funding rates between organisations.	Due to different hourly rates between both meant we needed to fight for same rate in order to pay PAs as counted. Took a long time to get through to CHC and for them to get what we needed many phone calls. Resolved eventually after months.	After being under reassessment for five years without an outcome it was frustrating and naturally exhausting for all involved. Rather than having a review each year full DTS's were done each time, very time consuming and draining, a	It wasn't just a review to check any changes it was a full DST again asking same questions as previous year without a decision being made. A lot of repetition telling story over again.

						couple of good experiences from workers CHC and social care but mostly negative not valuing individual/PAs or family	
Person 5 Carer/family member of someone in receipt of/being assessed for CHC funding	The identification of needs wasn't dealt with as an update before the DST. No need to deal with the checklist as CHC has been in place for some years and it was obvious needs hadn't reduced.		These comments relate to DST as the checklist wasn't necessary: The assessor showed empathy and patience in including my [family member] so [they] felt at ease. I was concerned about an example used though. Preparation /reports should include risk assessments to understand complexity of need. Can be difficult to have in depth conversations about my [family	This was communicated over eight weeks after the full assessment – recommend is four weeks. My [family member] was anxious as we had already been told the expected decision. [Their] financial concerns were high as that is an area [they] doesn't understand. Had to receive document to look at whether appeal is needed resulting in a		As the first process had not been reviewed, the care company have yet to be involved in community and reviewing care. Emphasis remains on parental involvement. Three young people share and changes to care packages impact on other individuals as a result.	None!

			member] as it raises [their] anxieties therefore important to have first part of process completed first.	hiatus. Fortunately, no reduction in package but needs are higher.			
Person 6 Carer/family member of someone in receipt of/being assessed for CHC funding		Last better than first, except when CHC nurse was suggesting withdrawal of epilepsy meds due to no seizures – this is due to meds.	Form insufficient space for 24 hour recording and information how to fill 24 hour. Not at all good.	Never received funding docs from CCG/CHC. Only Aault social care. Still do not know the split.		Package is great my worry is that in the current climate it will be reduced. Any reduction will make [their] total package unworkable.	
Person 7 Carer/family member of someone in receipt of/being assessed for CHC funding	Social care led.		Think the tool used is not accurate or fair reflection of need.	Because of DST funding decision is based on it not the reality	Misleading paperwork.		Ours have been full assessments every year due to social care not making a decision. Sometimes difficult to plan as need to do CHC & social care together.

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CHC NEWS

4th December 2018

What I want to know

what people said/feedback and what was done.

user experiences and reviews good and bad.

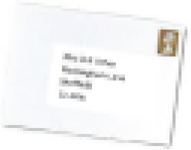
Resources created by users

How often to receive news

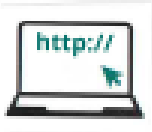
4 X Year

What I don't want to know or experience

Case studies.



How I want to be informed



- frequently to include immediate updates

Twitter/facebook threads, too

use other newsletters:- Parent/Carer forum & Carers Centre.

I had a CHC assessment ☐
I am the relative/carer of someone who had a CHC assessment ☑

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CHC NEWS

4th December 2018

What I want to know

- How peoples/individuals/citizens engagements and involvements in workshops are used to shape future changes in CHC and receive feedback throughout the process.
- Regular updates on how the project is going and chances to give feedback + input on any opinions throughout the project - Be involved throughout - true co-production.
- Timely + simple assessment + review processes. Not taking too much of an individual's time, informs them throughout and doesn't get them involved in financial discussions 'decision' appraisals they shouldn't have to

How I want to be informed

✉ EMAIL

How often to receive news

1 X Month

What I don't want to know or experience

- CHC using public involvement as a tick box exercise to meet targets.
- Being consulted about a project but not being able to see it through to the end.
- Don't want to belittled, treated like we don't know anything; to feel like my knowledge of an individual isn't important.
- Individuals being assessed not being treated as an equal, they have thresholds -

I had a CHC assessment ☐
I am the relative/carer of someone who had a CHC assessment ☑

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CHC NEWS

4th December 2018

What I want to know

I want it all available to access when I need it.

We only want anything at point of need

How often to receive news

Month as a routine but generally

What I don't want to know or experience

Excuses.

How I want to be informed

I had a CHC assessment ☒
I am the relative/carer of someone who had a CHC assessment ☐

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CHC NEWS

4th December 2018

What I want to know

- Key contacts (if changed)
- Anything at government and local government levels that will affect us - explain what it means to us.
- policy changes leading to practical changes.

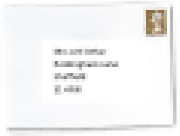
How often to receive news

Every 3 Month

What I don't want to know or experience

How I want to be informed

→



To alert to letter

I had a CHC assessment ☑
I am the relative/carer of someone who had a CHC assessment ☐

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CHC NEWS

4th December 2018

What I want to know

I want know what you know when we are in the same process

How often to receive news

Monthly

What I don't want to know or experience

waffle.

How I want to be informed

I had a CHC assessment ☐
I am the relative/carer of someone who had a CHC assessment ☑

Appendix 1: Participant information sheet

Continuing Health Care (CHC) Focus Group

Tuesday 4th December 2018, The Circle.

Welcome to today's focus group. We're really pleased that you've come along to share your experience and expertise with us.

Who are we and what are our roles?

NHS Sheffield Clinical Commissioning Group (CCG)

It's the job of Sheffield CCG to put into practice the national policy on NHS Continuing Health Care and funded nursing care.

They aim to ensure that fair and consistent decisions are made for all people applying for CHC and for patients and their families or carers to be treated with dignity and respect.

Hearing the views and ideas of people who have actually been through the process will help the CCG to do this better.

The CCG team are particularly keen to understand:

- How and when people should be asked about their experience of Continuing Health Care.
- How people would like the CCG to keep them updated with news and changes.

Healthwatch Sheffield

Healthwatch Sheffield is independent of the NHS and city council. We exist to help local people influence decisions about health and social care.

Recently we've been helping the CCG to listen to people's views on Continuing Health Care as it can be a sensitive and complex topic, affecting people when they are sometimes feeling at their most vulnerable

What will happen?

The focus group will be facilitated by Laura Cook and Margaret Kilner from the Healthwatch team and we'll be joined by three people from NHS Sheffield Clinical Commissioning Group (CCG):

- Sarah Neil is the Quality Manager for Patient Experience.
- Paul Higginbottom is the Senior Programme Manager for Ongoing Care.
- Diane Holley is a nurse and the Learning Disabilities Team Leader.

Sarah, Paul and Diane are here to listen and might get involved by taking notes or answering specific questions about the CHC process.

We expect the session to work like this, but if you want to make suggestions, please feel free.

- 1pm	Introductions and welcome
- 1:15pm	Plotting experiences and sharing views
- 1:55pm	Comfort break
- 2:10pm	Monitoring the quality of CHC assessments and reviews
- 2:35pm	Communication and information
- 3pm	Close

If you need to nip out to the loo or get a drink at any time, please feel free.

Laura and Margaret will do their best to make sure everyone gets chance to have their say and we've designed two activities to help with this.

If after the focus group you still have ideas you want to share, please get in touch. These are our contact details:

Healthwatch Sheffield
The Circle, 33 Rockingham Lane, Sheffield, S1 4FW
phone: 0114 253 6688, text only: 0741 524 9657
email: info@healthwatchsheffield.co.uk website: www.healthwatchsheffield.co.uk

We plan to get in touch with everyone taking part today to let you know how your input will make a difference for other patients and their families and/or carers.

This may involve your contact details being shared between Healthwatch Sheffield and Sheffield CCG. If you would prefer not to hear from us or for your information to be shared. Please let Margaret or Laura know.

With thanks,
Margaret Kilner and Laura Cook, Healthwatch Sheffield