Switchboard

Connecting you to LGBTQ support

REPORT ON LGBTQ+ COMMUNITIES AND THE CARE QUALITY COMMISSION

April 2022

Introduction

Switchboard is a charity that has been listening to, supporting and connecting lesbian, gay, bisexual, trans and queer communities since 1975. Originally a helpline, we have grown to deliver lots of additional services by and for LGBTQ people in Sussex. Our services include older person and dementia , disability and neurodiversity, trans social prescribing, domestic abuse services as well as our health inclusion and training projects.

We were asked by Healthwatch Brighton and Hove to engage LGBTQ+ communities in Brighton and Hove about feeding back to the Care Quality Commission (CQC).

We shared the Healthwatch survey across our communications and organised engagement activities. Focus groups were advertised using our social media presence and internal communications to reach people using our services.

We consulted with 21 members of LGBTQ+ communities in 3 focus groups. The first one on March 23rd was face to face with 3 attendees, second was online for people with disabilities and neurodivergence on March 28th with 7 attendees and a third online with 5 people aged 16-25 yrs on 30th March. The rest were one to one interviews at the request of participants and were between 23rd-31st March. We offered vouchers to people for their contribution.

We also ran polls for those aged 16-25 via our social media channels as these have proved particularly popular with younger LGBTQ+ people.

Many of the participants reported that they valued being asked their opinions.

"It's great that you're putting together these focus groups and feeding back. Clearly many disabled LGBTQI+ folks are having similar poor experiences with NHS and social care treatment"

- Focus group attendee

BARRIERS TO REPORTING

Lack of knowledge of CQC

- Only four of the participants had heard of the CQC and these were individuals who knew about it for professional reasons

- It was thought that the name of the CQC doesn't reflect what it does

- Only one attendee had reported to the CQC. Their experience was straight forward, however they were frustrated that there was no further feedback or reassurance of action taking place

- No participants had ever been told about the CQC when they had accessed health and social care services or when they had made a complaint

- Several participants felt that people within health and social care organisations do not understand the role of the CQC and the process for feeding back

- Many of the 16-25 year old participants did not know they could feedback about healthcare even to Patient Advice and Liaison Services (PALS)

- There were suggestions that the CQC could be more proactive and agile to be able to ask service users regularly to feed back

"People don't feel comfortable feeding back to something they don't know"

BARRIERS TO REPORTING CONT.

Emotional Burden

- All of the participants talked about not having the emotional energy to give feedback particularly after a negative experience

"The idea of having to delve into it again.. having it all brought up again to make a complaint felt too complicated difficult and raw"

"When you have a bad experience you are demoralised"

- People reported experiencing trauma from health and social care and didn't want to relive that trauma

- All of the trans/non binary participants reported being misgendered, being asked inappropriate questions irrelevant to their care and challenges related to their gender identity

- It was generally thought that there should be more recognition of the emotional burden of providing feedback and the need for support when doing this

- There was a general consensus of feeling that complaints were generally a burden to health and social care professionals as they caused more work

"Having the energy. Every day misgendered or repeated micro aggressions, facing difficulty and stigma so having to challenge people is exhausting"

Barriers to Reporting Cont.

Fear of CQC not understanding LGBTQ+ issues and experiences

- All participants had experienced heteronormative assumptions from health and social care and felt any organisation such as the CQC would be the same

"I worried that the feedback wouldn't be received in a warm and supportive way or by someone who didn't understand LGBTQ+ issues"

- There was consensus across the groups and is often highlighted in research that LGBTQ+ people are more likely to live on their own particularly in older age and don't have support to raise concerns

- Many of the participants aged 16-25 reported not having parental support so nobody to help empower them to provide feedback

- Trans and non-binary people worried about when feeding back that they would have to educate the CQC about their gender and body parts to explain the issue

"I worried would the people at the CQC understand what it is like to be a trans person and therefore would they actually listen to me and appreciate the challenges I face accessing health and social care?"

"I would like... a specific LGBTQ+ person who was on my side, the problems I have as a trans person are not common or normative so harder to find a pathway to help [....] I need to someone to support me not just signpost"

Barriers to Reporting Cont.

Fear of negative impact on health and social care provision

- It was reported that several people were afraid of health and social care professionals and many feared repercussions from reporting negative experiences

- Trans people in particular reported fearing they would be denied hormone therapy or trans affirmative support if they reported negative care

Previous experience of feeding back about care in other ways has not been successful

- Of the people who had provided healthcare feedback via PALS and service specific complaints procedures the majority had not had a satisfactory outcome

> *"I was made to feel that my voice was a drop in the ocean"*

Concern for health and social care providers

- Respondents reported worries that their complaints would undermine the NHS and were acutely aware that in a lot of circumstances, healthcare professionals were doing the best they could with the resources they had

- This worry and fear of "bothering" health professionals made it less likely for people to want to report to the CQC when things went wrong

> *"Is there going to be a space for educating the healthcare professional rather than penalising?"*

PREFERENCES FOR FEEDING BACK

- The majority of participants felt that a simple online form would be optimum with a small number of drop down questions and then space for free hand

- Choice was key to all participants- they thought there should be an option for phone and video call for people with limited incomes ,those who are digitally excluded, and people with disabilities

> *"I would feel empowered if there was an advocate with lived experience or someone who can listen and signpost and support in managing the 'system' "*

- Many when asked about the current form felt it was really inaccessible

- There were suggestions for there to be a QR code which is available across all services at point of delivery as this would encourage people to give feedback

- One person suggested the CQC should have a 'Trust Pilot' site

- Most mentioned having the feedback request in an App which could maybe sit in the NHS App as since Covid more people are comfortable with using this

- Some suggested a short form or live chat function so you know beyond doubt that someone has read your message

- Most participants thought there should be an option for anonymity as not everyone was 'out'

> *"Would be good if it could be integral to the NHS app as that is a something used already eg 'How was your healthcare today?' "*

ACTION AFTER REPORTING

- 100% of participants wished to have their feedback acknowledged with a clear statement of what happens next

- 100% of participants also wanted to know that some action had taken place following the feedback. They acknowledged that this could not be in detail but wanted to see impact from their input, which as discussed previously was often an emotional burden

- 100% of participants wanted acknowledgement when giving negative feedback that they were being heard, understood and wished to have an acknowledgement if care was unacceptable

- They also wished to know that positive feedback would go directly to the service involved

- All people liked the format of "You Said, We Did"

- Some people felt that they would rather receive a phone call from an allocated person before a letter is sent out

- One person felt they would specifically not wish to speak to anyone but do everything online

- Generally people felt they would be much more likely to provide both positive and negative feedback if they had seen an outcome from feedback

"I would like an email response thanking me for feedback – don't just want a sorry but want to know there has been a change or an improvement as a direct response from feedback"

Other Issues

Out of these focus groups and interviews there were several issues raised which require further exploration:

- Heteronormative assumptions were made with partners being assumed to be friends or siblings

- An ignorance about specific health issues related to all aspects of trans health care and being 'outed' inappropriately

- An ignorance about LGBTQ+ people particularly related to fertility issues, prenatal care, and cancer screening

- Health and social care professionals stereotyping people based on ethnicity and age

- People with disabilities being patronised particularly if in a wheelchair

> *"Being told you are a waste of resources is common for people who are disabled and trans. Demoralising and dehumanising...put up with years of micro aggressions...*
> *we are allowed to be frustrated!"*

- A reluctance of health care professionals to discuss issues related to sex such as surgical procedures directly impacting on sexual function

- Younger people in particular not knowing that they could give feedback about care

- Those who had complained through PALS did not feel the process was transparent or LGBTQ+ affirmative due to a lack of understanding and education

- Overwhelmingly people wished to have LGBTQ+ health navigators to support and enable them to navigate healthcare systems. Those people who had found a health and social care professional to champion them found their experience became much more positive

SUMMARY

The findings from this engagement about feeding back to the CQC were consistent across all of the focus groups, one to one interviews and polls.

One of the most significant findings was the lack of awareness and knowledge about what the CQC is and it's function. There was a consensus that being made aware of it at point of care would make people more likely to provide both negative and positive feedback.

There was a strong call for assurance that team members at the CQC are educated about what it is like to be LGBTQ+ and the particular challenges experienced . This includes visible LGBTQ+ people working for the CQC and the potential for a specific LGBTQ+ reporting avenue. This could also be achieved by working with LGBTQ+ charities who could be a point of initial feedback and advocacy.

The importance of having a 'menu' of ways to provide feedback to suit the individual was emphasised and acknowledgement and an action following feedback was also seen as important.

There was also a consensus on the importance of collecting information about gender and sexuality, both to deliver person centred care and to ensure that we are seen and counted.

It became apparent that many of our participants had experienced episodes of negative health and social care which was influenced by their gender and or sexuality.

In the process of this engagement there was narrative about poor experiences of health and social care and the specific challenges faced by LGBTQ+ people navigating services.
This is something which Switchboard will discuss as part of their separate CCG commission and is also an opportunity to work with Brighton and Hove Healthwatch in the future.

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