



NHS COMPLAINTS, CONCERNS AND FEEDBACK RESEARCH REPORT

JANUARY 2017

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LGBT Health and Inclusion Project NHS Complaints, Concerns and Feedback Research Report January 2017



The LGBT Health and Inclusion Project

Brighton and Hove NHS Clinical Commissioning Group (BH CCG) and Brighton and Hove City Council (BHCC) have commissioned the [LGBT Health and Inclusion Project](#) at Brighton and Hove [LGBT Switchboard](#) to conduct a series of consultation and engagement activities with local lesbian, gay, bisexual and trans people (LGBTQ) people. The aim is to use the information gathered to feed into local service commissioning, planning and delivery.

Please note, the following report presents information about the consultation and engagement work conducted by LGBT HIP, and should not be taken as a position statement of Brighton and Hove LGBT Switchboard or of any participating organisation.

1. INTRODUCTION

This report presents data from an online survey of LGBTQ people in Brighton and Hove on the opinions and experiences of providing feedback, raising concerns and making complaints about NHS services in Brighton and Hove. The report also presents case studies drawn on feedback gathered through 1:1 interviews with three local LGBTQ people with relevant experience.

1.1 Background

The [National Health Service \(NHS\) constitution](#) states 'You have the right to access NHS services. You will not be refused access on reasonable grounds' and 'You have the right not to be unlawfully discriminated against in the provision of NHS services including on grounds of gender, race, religion or belief, sexual orientation, disability (including learning disability or mental illness) or age¹.'

Under the Provision of Goods and Services Act 2007, it is illegal for lesbian, gay and bisexual people to be denied access to services on the grounds of sexual orientation. Discrimination in healthcare is a problem faced by many LGBTQ people, in spite of legal protections. Results of [national research](#) conducted by Stonewall report that of their respondents 34% of gay and bisexual men and 54% of lesbians and bisexual women who had accessed healthcare services in the past year had negative

¹ <https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england>

experiences related to their sexual orientation². In an [Equalities Review report](#), Whittle et.al found that trans people frequently have bad experiences with healthcare providers. 22% of respondents to the 2007 study felt that being trans affected the way they could access routine (non-trans related) services, 29% of trans respondents felt that being trans adversely affected the way they were treated by healthcare professionals in accessing non-trans related routine treatment on the NHS and 17% of respondents had experience of being denied services in the general health sector by doctors or nurses who did not approve of gender reassignment³.

The [Trans Parliamentary Enquiry](#) (2015) found that trans people experience worse health (both physical and mental) than the general population, which is likely to be substantially due to the direct and indirect effects of the inequality which trans people experience. The enquiry report details many of the significant difficulties that trans people face when accessing general NHS services. Jess Bradley, of Action for Trans Health, described a “lack of understanding and lack of cultural competency around trans issues” in the NHS. The Enquiry also noted that there appeared to be particular problems with the attitude of some GPs, which can cause significant difficulties given their role as “gatekeepers” to other NHS services, including Gender Identity Services.⁴

Local LGBTQ research project [Count Me in Too](#) (CMIT, 2008) reported that LGBTQ people were more likely to say their health was poor when compared with the general population⁵, and that LGBTQ people could experience difficulties with their GP in relation to their gender or sexuality. The qualitative findings of the research also noted how LGBTQ people can experience difficulties with their GPs and source LGBTQ friendly GPs, as well as the imperative for some groups to tell their GPs about their sexual/gender identities.

Stonewall found in their report [Unhealthy Attitudes](#) that there is a lack of confidence among health and social care staff, including those most relevant health and social care practitioners with direct responsibility for patient care, in their ability to understand and meet the needs of LGBTQ patients and service users. They recommended that health and social care organisations should update patient complaints procedures and communicate to all staff that homophobic, biphobic and transphobic complaints will be taken seriously⁶.

1.2 Aim

The aim of this research exercise was to gather LGBTQ views and experiences of providing feedback, raising concerns and making complaints about NHS services in Brighton & Hove. This is to make sure that NHS and independent complaints services in the city are inclusive and that LGBTQ people’s voices are heard in the process of developing and implementing any changes.

² Hunt, R. & Fish, J. (2008) Prescription for Change. Lesbian and Bisexual Women’s Health Check 2008. Stonewall: London

³Whittle, S., Turner, L. & Al-Alami, M. (2007) Engendered Penalties: Transgender and Transsexual People’s Experience of Inequality and Discrimination

⁴ <http://www.publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/39002.htm>

⁵ Browne, K. & Lim, J. (2008) Count Me In Too: General Health additional findings report, University of Brighton: Brighton.

⁶ Somerville, C. (2015) Unhealthy Attitudes: The treatment of LGBT people within health and social care services

2. METHOD

2.1 Survey

Questions were developed in line with questions suggested by the Clinical Commissioning Group (CCG) and adapted to reflect concerns specific to the LGBTQ population. The survey was conducted using SurveyMonkey over a period of one month in November 2016. Paper copies of the survey were also advertised alongside links to the SurveyMonkey online form, and offered to local community organisations for distribution to their clients, but none were requested. The survey was promoted and distributed through a variety of channels including the LGBT HIP members' list, LGBT HIP's social media presence on Facebook and Twitter, email lists for Community Works, Community Base and LGBT Switchboard staff and volunteers.

Responses have been analysed and reviewed by the LGBT HIP Support Officer, Chris Brown, and qualitative responses were reviewed to identify key themes and extend quantitative findings.

2.2 Case studies

In addition to the survey, three case studies were carried out with local LGBTQ individuals with relevant experiences. The case study interviews were advertised through the same routes as the survey.

3. DEMOGRAPHICS

3.1 Case Studies

LGBT HIP carried out three interviews with members of the local LGBTQ community who responded to a callout for people willing to share their experiences of either making a complaint about NHS services in Brighton & Hove, or of barriers to making a complaint. The demographics of the interviewees were as follows:

- a 67-year old gay man who has spent some time in hospital
- a 40-year old non-binary queer person with Asperger Syndrome
- a 37-year old FTM male with physical health and mental health problems

3.2 Internet Survey

Participants were all first presented with an initial screening question, which limited the sample, by self-exclusion of participants who did not meet certain criteria. The screening question limited the sample to *'lesbian, gay, bisexual, transgender and queer people who live, work, study or socialise in Brighton and Hove'*. After this question there were a total of 38 eligible respondents. At the end of the survey, data was collected on participants' age, sexual orientation, gender identity, ethnicity and disability.

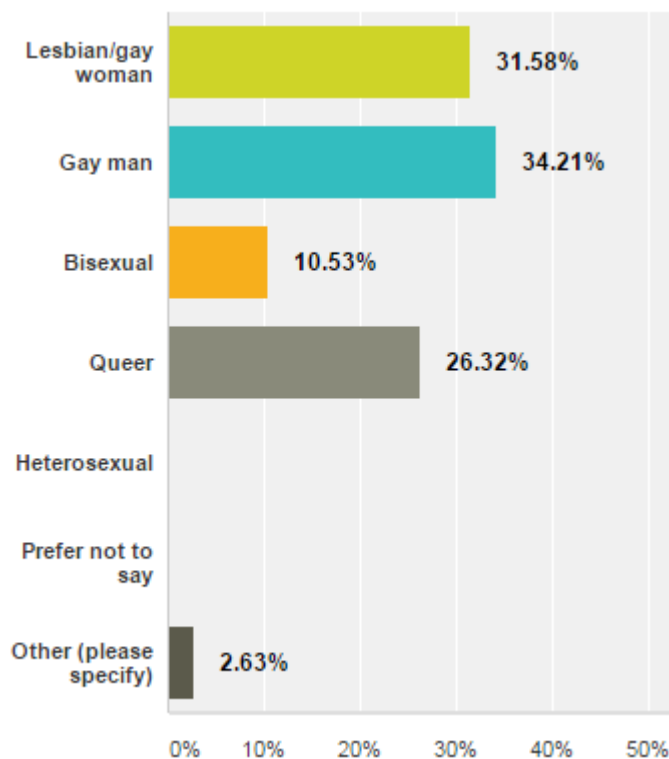
Age (38 respondents)

Participants were asked to select their age from a range of banded options. The age distribution was fairly evenly spread across the groups with the highest proportion of respondents between the ages of 45 and 54. 5% (2) of respondents were aged 18-24. 16% (6) were 25-34 years old. 21% (8) were 35-44. 34% (13) were 45-54. 16% (6) were 55-64. 8% (3) were 65-74, with no participants aged 75 or over.

Answer Choices	Responses
18-24 (1)	5.26% 2
25-34 (2)	15.79% 6
35-44 (3)	21.05% 8
45-54 (4)	34.21% 13
55-64 (5)	15.79% 6
65-74 (6)	7.89% 3
75+ (7)	0.00% 0
Prefer not to say (8)	0.00% 0
Total	38

Sexual Orientation (38 respondents)

Participants were asked to select which of the orientations listed described them and were permitted to select more than one option.



32% (12) indicated that they identified as a lesbian or gay woman

34% (13) indicated that they identified as a gay man

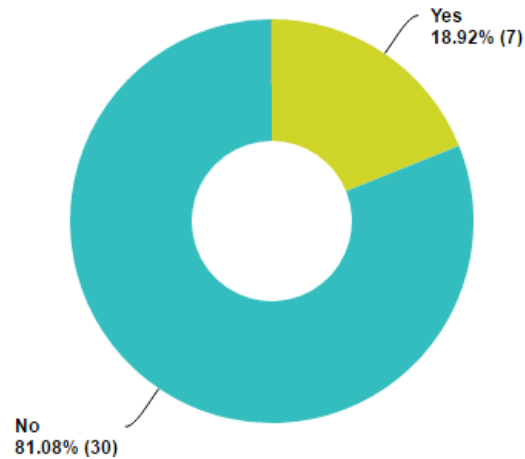
26% (10) indicated that they identified as queer

11% (4) indicated that they identified as bisexual

3% (1) respondent indicated that they identified with an 'other' sexual orientation which was not listed: pansexual

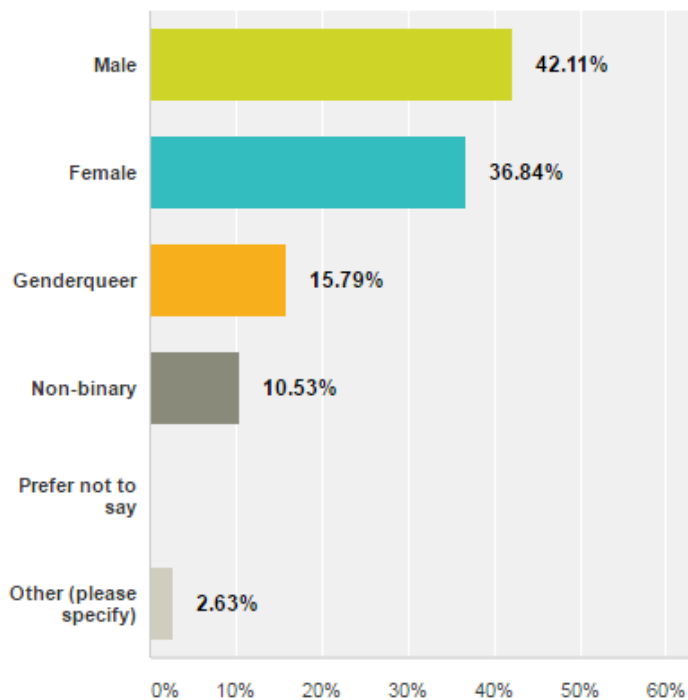
Transgender (37 respondents)

Participants were asked: 'Do you identify as transgender or trans, or have you in the past?' 19% (7) of respondents to this question indicated that they did identify as transgender or trans or that they had in the past.



Gender Identity (38 respondents)

Participants were asked to select which of the gender identities from the following list best described them: male, female, genderqueer, non-binary, other, or prefer not to say. Respondents could select more than one option and were also presented with an open field in which to describe other gender identities which did not fit into those options.



42% (16) of respondents identified as male

37% (14) of respondents identified as female

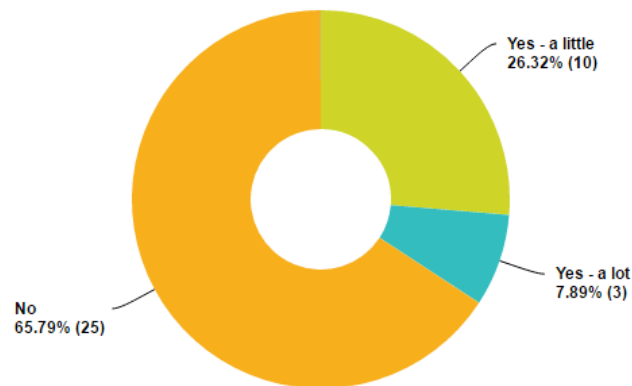
16% (6) of respondents identified as genderqueer

11% (4) of respondents identified as non-binary

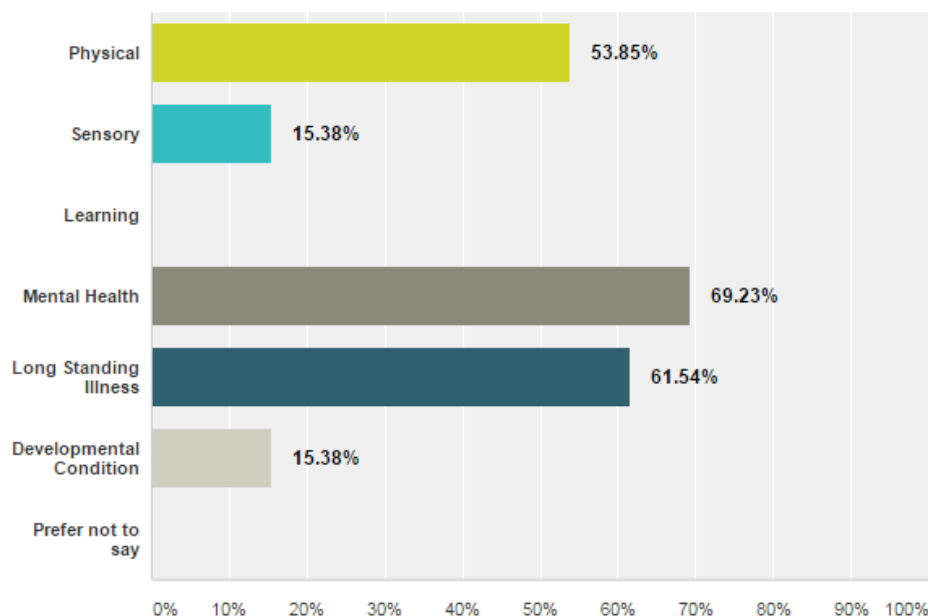
3% (1) identified with an 'other' gender identity which was not listed: agender

Disability/Long Term Health Condition (38 respondents)

Participants were asked: *Are your day to day activities limited due to being a disabled person?*



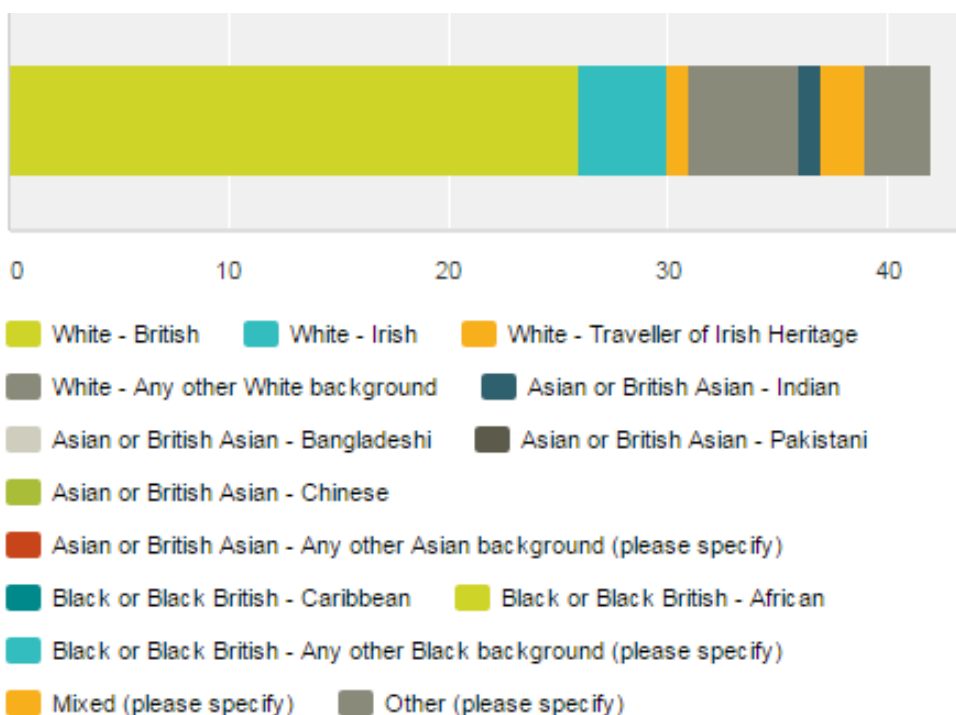
In total, 34% (13) of respondents indicated that their day to day activities were limited due to a disability. 27% (10) of respondents indicated that their day to day activities were limited a little and 8% (3) indicated that their day to day activities were limited a lot.



Of those respondents (13) who indicated that their day to day activities were limited due to a disability, 69% (9) indicated they had a mental health condition; 62% (8) indicated they had a long standing illness; 54% (7) indicated that they had a physical disability; 15% (2) indicated that they had a sensory disability and 15% (2) indicated that they had a developmental condition.

Ethnicity (38 respondents)

Respondents were asked to select from a list of terms to describe their ethnic background. 69% (26) identified as being of White British heritage. 11% (4) of respondents identified as being of White Irish heritage and 3% (1) as White - Traveller of Irish Heritage. 13% (5) of respondents identified as being from any other White background. 3% (1) indicated they were Asian or British Asian – Indian. 13% (5) of respondents indicated that they were of mixed or 'other' heritage; the three people who specified their background stated French, Romani and Jewish/Middle Eastern/White. The total percentage of respondents identifying as being of BME heritage was 42% (16).



Neighbourhoods (38 respondents)

Respondents were asked to indicate the first four digits of their postcode. 8% (3) of respondents indicated that they lived outside of Brighton & Hove.

Answer options	Response percent	Response count
BN1 1	2.63%	1
BN1 2	2.63%	1
BN1 3	5.26%	2
BN1 4	7.89%	3
BN1 5	2.63%	1
BN1 6	2.63%	1
BN1 7	2.63%	1
BN1 8	0.00%	0
BN1 9	0.00%	0
BN2 0	2.63%	1
BN2 1	10.53%	4
BN2 3	7.89%	3

BN2 4	0.00%	0
BN2 5	5.26%	2
BN2 6	0.00%	0
BN2 7	0.00%	0
BN2 8	2.63%	1
BN2 9	0.00%	0
BN3 1	13.16%	5
BN3 2	7.89%	3
BN3 4	2.63%	1
BN3 5	5.26%	2
BN3 6	2.63%	1
BN3 7	0.00%	0
BN3 8	0.00%	0
BN41 1	2.63%	1
BN41 2	0.00%	0
BN41 3	0.00%	0
BN41 4	2.63%	1
BN41 5	0.00%	0
BN41 6	0.00%	0
BN41 7	0.00%	0
BN41 8	0.00%	0
BN41 9	0.00%	0
I live outside Brighton & Hove	7.89%	3

4. FINDINGS: CASE STUDIES

The three interviews that were carried out are outlined in the case studies below.

4.1 Case Study One

The first case study interview was with a 67-year old gay man who had two experiences of homophobic treatment in a hospital setting.

In the first instance, some years ago, he was taken to Accident and Emergency with severe injuries following an assault in a local gay club. The nurse in charge called to a colleague across a room of patients and staff, "Don't spend too much time with him, he's probably been hanging around in the toilets anyway." This person felt very humiliated, and that the nurse had acted out of homophobia. His partner was furious but neither of them made a complaint. No staff members challenged the nurse on her attitude.

The second incident happened just over a year ago when he was urgently admitted to hospital with pneumonia. The ambulance driver asked this person's partner what their relationship was, and the partner clearly answered 'civil partner.' However, the driver seemed to have written down 'brother,' and on the several occasions his partner visited him the nurse on the ward would call across the ward, in front of everybody, to ask what their relationship was. In answering 'civil partner' again and again, he was frequently being forced to 'out' himself as gay. Nobody else on the ward had this experience. Again, while his partner was very angry, no complaint was made.

In both cases there were two barriers to making a complaint. Firstly, he was simply not aware of the opportunity to make a complaint, or the process for doing so. Secondly, he was very clear that as a gay man growing up in an era when gay sex was a criminal act, he had learned to expect homophobia in every aspect of his life and felt that internalised homophobia was an issue that stopped him feeling he had the right to complain about homophobia in a healthcare setting. He would have been more likely to think about complaining had the problem been with his physical healthcare rather than a homophobic attitude.

Asked what would have made him more likely to complain, he said that seeing leaflets or posters on site at the hospitals would have helped, and also seeing information about the complaints process in LGBTQ magazines and/or websites. He also thought that LGBTQ awareness training for staff might be useful though he assumed they would already have some degree of awareness already.

4.2 Case Study Two

The second interview was with a 40-year old non-binary queer person with Aspergers who uses the pronouns she/her. She encountered what she felt was discriminatory treatment in the audiology department at Royal Sussex County Hospital, following a referral from her GP.

This person's audiology referral had been made for further testing as her GP suspected she had Auditory Processing Disorder (APD). The audiologist only carried out standard hearing testing, despite the letter from the GP asking for further investigation into APD and she requested APD testing in the appointment. Following the standard tests the clinician asked 'How is your Aspergers at the moment?' inferring that any hearing issues were due to autism. This person felt that she would have received the correct APD testing, but for her diagnosis of an autism spectrum condition.

This person wanted to complain but wasn't sure of the correct route, or whether the desired APD test would be an outcome of a complaints process. She emailed PALS and was sent a complaints process guide; however, she wanted help to actually make the complaint. PALS signposted her to Healthwatch and ICAS. Healthwatch suggested she carry out a Freedom of Information (FOI) request to find out if others had been offered APD testing. Healthwatch also suggested she contact PALS and ICAS. ICAS asked her whether she had considered writing a complaint letter or contacting PALS.

She noted that all the support agencies offered her information about the complaints process and signposted to each other, but none offered her support with actually making the complaint. She did not find these agencies helpful. When she wrote a complaint letter to audiology she did not at any point receive acknowledgement or a response. Ultimately her GP referred her to an audiology department in London where the correct tests were carried out and APD was diagnosed and treatment offered. She had to pay travel costs for this 2.5 hour round trip. She was angry that she had to go to London for services she should have received in Brighton: *'They just didn't listen to me – the whole thing felt like such a battle.'*

The experiences of trying to complain and travelling to London for healthcare took time, energy and money and the experience worsened her depression. This person feels she is now less likely to make a complaint, saying *'The whole thing was a lot of stress, effort and emotional labour. I think knowing the toll it takes I wouldn't bother to do it again.'*

Asked what changes would make this process easier, she suggested an independent body that monitors complaints and can impose fines if targets (e.g. response times) are not met, as there had been no penalty for the lack of response to her complaint. She also suggested staff training about autism spectrum conditions since her Aspergers was the implied reason for not testing for APD, although there is a known co-morbidity with autism spectrum conditions and APD. She would have been more likely to complain via MindOut if they offered general/healthcare advocacy as she's had an excellent experience with their mental health advocacy.

4.3 Case Study Three

The third interview was with a 37-year old FTM male, who has 17+ years' experience of accessing healthcare services in the city, including general practice, trans, mental health and many more.

Over this period, he has on several occasions had cause to make a complaint, for reasons including being spoken to rudely and with disrespect, not receiving the appropriate treatment(s) in a timely manner, self-diagnosed issues being ignored and being 'talked down to.' He has multiple and complex healthcare needs with several different conditions and diagnoses that have a significant impact on his life. Of his experience of accessing healthcare as a trans person, he said that his experience of female healthcare had not been good, but that trans healthcare felt like 'the bottom of the pile,' with GP's having no idea about treatment or pathways, and that he had similar problems with gynaecology and endocrinology. On multiple occasions he experienced doctors as patronising, condescending and treating him as a hypochondriac without investigating his healthcare concerns.

Following one particular incident, he mentioned to a healthcare practitioner that he was so frustrated that he was considering suing the NHS, but was strongly dissuaded from doing so, rather than having his concerns listened to and a complaints process offered. He noted that in general, receptionists often made things worse by being disrespectful and obstructive.

This person noted that multiple barriers prevented him from feeling able to make a complaint. These included his dyslexia, his socioeconomic status, his fear that complaining would have negative

repercussions for his healthcare, being dissuaded from doing so, his belief that it wouldn't change anything and his concern about not being able to produce evidence of conversations. He said:

“Had it not been for taking friends to appointments with me and being ‘pushy’ I would have been less likely to access treatment and support. It’s easier if you are middle class, can talk to the doctors on their level and have family to come to all your appointments. If not, you don’t have the same capacity to pursue healthcare.”

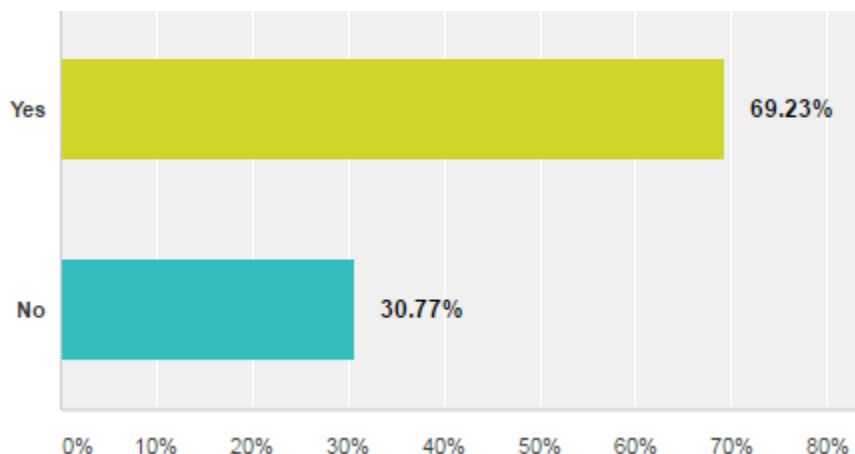
The impact of these problems with his care and of not making a complaint has been severe and enduring. He says, “I’m 37 and half of my life has been trashed by the medical system.” He believes that better healthcare might have prevented some of his health conditions worsening to the extent that they have. The attitudes he has experienced have affected his self-esteem, impacted on his health (particularly adding to his anxiety and depression), stopped him visiting his doctors and delayed treatments that could have significantly improved his quality of life. He feels that doctors have often focused on his mental health to the detriment of his physical health.

Asked what would help him make a complaint, he said that having someone independent to talk to would be useful – he was not sure he could trust an NHS staff member. He suggested that having ‘something less scary than writing letters’ would make it easier and that a central point of contact telephone number that he could call to have the complaints process explained would be helpful. He also suggested patients could receive a text inviting more feedback than just a score would help him, and a YouTube link explaining how to make a complaint, as a video would be more accessible to people with literacy challenges. He thought routine recording of appointments would help patients recall their sessions and be able to evidence a complaint if needed.

5. FINDINGS: INTERNET SURVEY

5.1 Awareness of NHS Complaints Process (39 respondents)

Participants were asked ‘Did you know that there is an NHS complaints process that you can use when things don’t go as well as expected with your health care, or if there is a problem?’ 69% (27) of respondents were aware that the process existed, with 31% (12) respondents reporting that they were not aware.

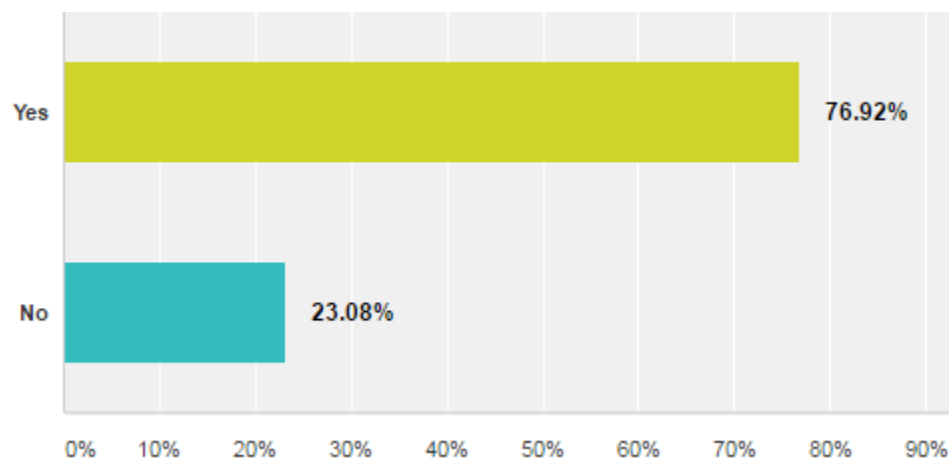


Of those who commented on how they knew about the NHS complaints process (18), five mentioned that they are aware of it because they work within the NHS. Three knew about the process because of their work and two would use the internet to find out. Comments included:

- “ Internet search and reading - there are many different ways to 'complain' - the 'process' is not the same across NHS organisations and B&H CCG have contradictory information about their complaints process. CQC responds fast.”
- “ I currently work within the healthcare setting at management level and am aware of this process.”
- “ I've had to complain about the treatment I've received on several occasions before.”

5.2 Willingness to make a formal complaint using the NHS complaints process (39 respondents)

Participants were asked ‘Do you think you would make a formal complaint using the NHS complaints process if you were unhappy about your care, or someone else's care?’ 77% (30) of respondents stated their willingness to complain, with 23% (9) answering ‘no’.



The survey invited the nine participants who would not make a complaint to comment on the barriers that stopped them being prepared to do so. Two participants had prior experience with making a complaint and had been put off making a future complaint. One said:

- “I’ve contacted them before. They tell you to go back to where you started and they are officious not helpful, they seem to be working through procedure not trying to help.”

A third person said they would target their complaint at senior management:

- “ Having said no, I might, but I would make sure my complaint was worth the bother in the first place, and I would aim it at senior management, as in my experience the trouble almost always comes from the top, not from the front line staff who are working under the most dreadful pressure at the best of times.”

Two people commented on being unsure of the correct procedure for making a complaint, while another person stated that they simply did not have a lot of confidence in the complaints process. For another person, the key barrier was their concern about their emotional and physical resilience.

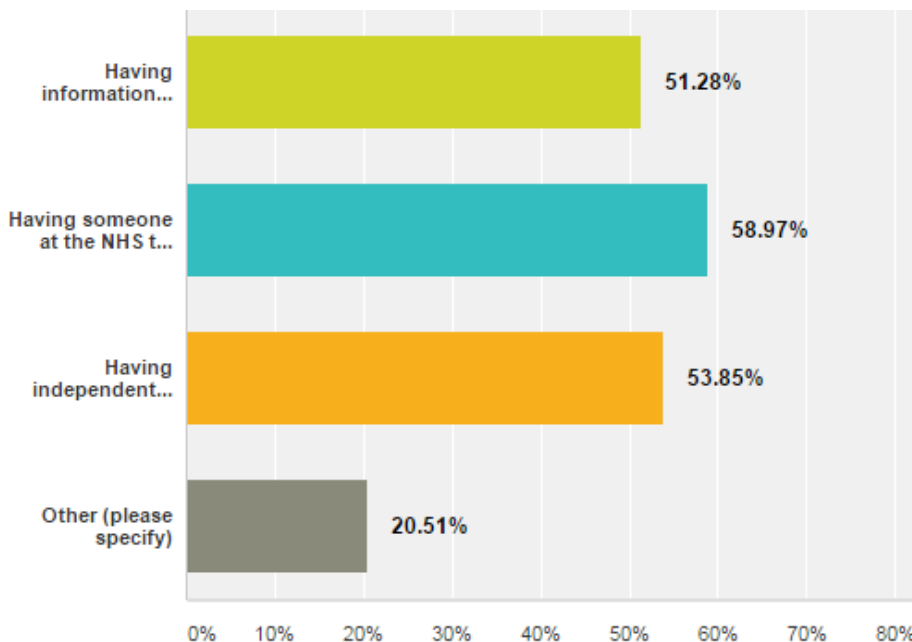
Another respondent was concerned about the repercussions of making a complaint:

“Retribution. NHS in Brighton and Hove is a small community in terms of senior people and it is well-known that complainers are targeted across NHS operations.”

5.3 Resources that would encourage respondents to make a complaint to the NHS in Brighton & Hove (39 respondents)

Participants were asked, ‘What would encourage you to make a complaint to the NHS in Brighton & Hove?’ They had four options, of which they could select as many as applied:

- Having information about the NHS complaints process in an accessible format
- Having someone at the NHS to talk to initially about the complaint
- Having independent support with using the NHS complaints process
- Other (please specify)



59% of respondents (23) said they would find it helpful to have someone at the NHS to talk to initially about the complaint. The second most selected category, with 54% (21) of respondents choosing it, was ‘having independent support with using the NHS complaints process.’ 51% (20) of respondents would be encouraged to complain by having information about the NHS complaints process in an accessible format.

21% (8) of respondents selected ‘Other’ and left comments about what would encourage them to make a complaint to the NHS in Brighton & Hove. For one participant it was important to have greater clarity about the process itself:

“Having the process easier to understand, having clear timescales for responses and what are reasonable expectations for remedying the issue complained about.”

Two people would find it helpful if complaints processes were available in different formats and accessible through diverse routes:

“ Having different methods to report via i.e.: online, text...survey, phone, face to face, BSL etc...
Being aware of advocacy orgs available that could offer further support with the process.”

For one person it was important to make sure they felt their complaint would have an impact, and that independent agencies were best placed to help complaints to be effective. One person also felt independent organisations were best placed to help but may not have an authentic desire to help, and another wanted to be sure that their complaint would be taken seriously.

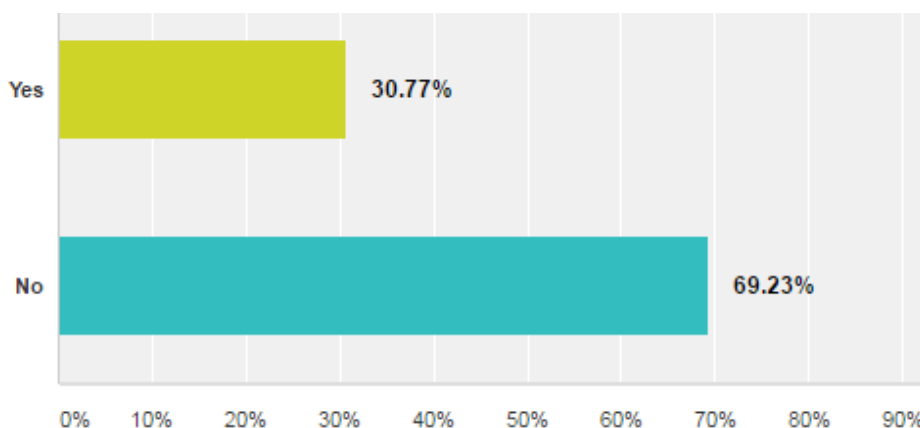
Finally, one person commented that an evidence-based process would encourage them to complain:

“ Evidence that the process is audited by external qualified professionals who belong to recognised professional bodies; that those in charge of the process are held accountable for delivering the process professionally, ethically and under the standards contained in the NHS Constitution; that privacy of those using the process is protected; ethical leadership showing that previous complaints have been taken forward and there has been learning (evidenced by changes) and that this is not a tick-box exercise to bolster KPI.

5.4 Knowledge about how to make a complaint about NHS care in Brighton & Hove (39 respondents)

Participants were asked, ‘Do you know how to make a complaint about NHS care in Brighton & Hove, should you need to?’

31% (12) answered that they did know how to make a complaint, and 69% (27) indicated that they didn’t.



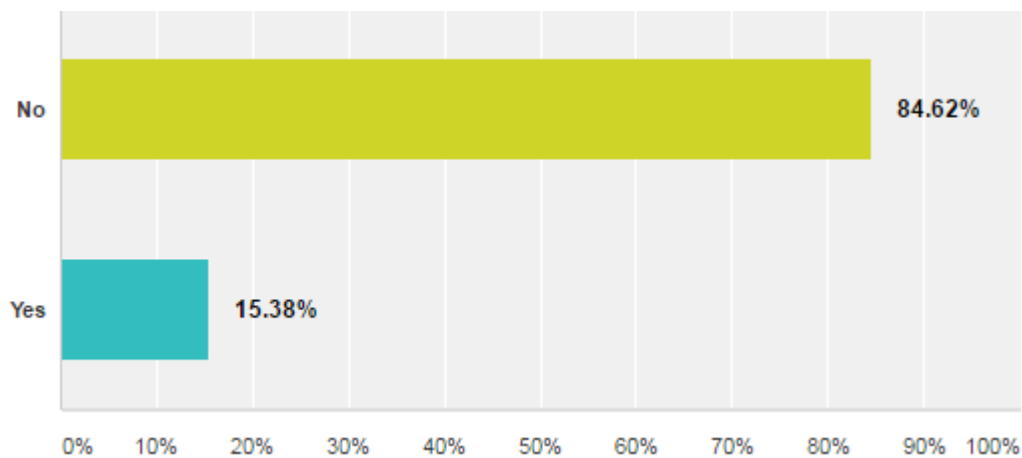
Participants who indicated that they knew how to make a complaint were asked to describe how they would do so. 10 people left a comment, with two referring to the NHS Brighton & Hove website. Six responses mentioned PALS, Healthwatch or ICAS, although not all of them were certain about what the process should be:

“ I’m not sure if I have to complain to the individual NHS provider e.g. GP surgery or hospital department, or if I have to go direct to PALS.”

One respondent would bypass the NHS or independent local complaint support agencies and go direct to the Care Quality Commission (CQC) and their local MP.

5.5 Incidence of complaints made to the NHS in Brighton & Hove (39 respondents)

Survey participants were asked ‘Have you ever made a complaint to the NHS in Brighton & Hove?’ 85% (33) said they hadn’t, and 15% (6) said they had.



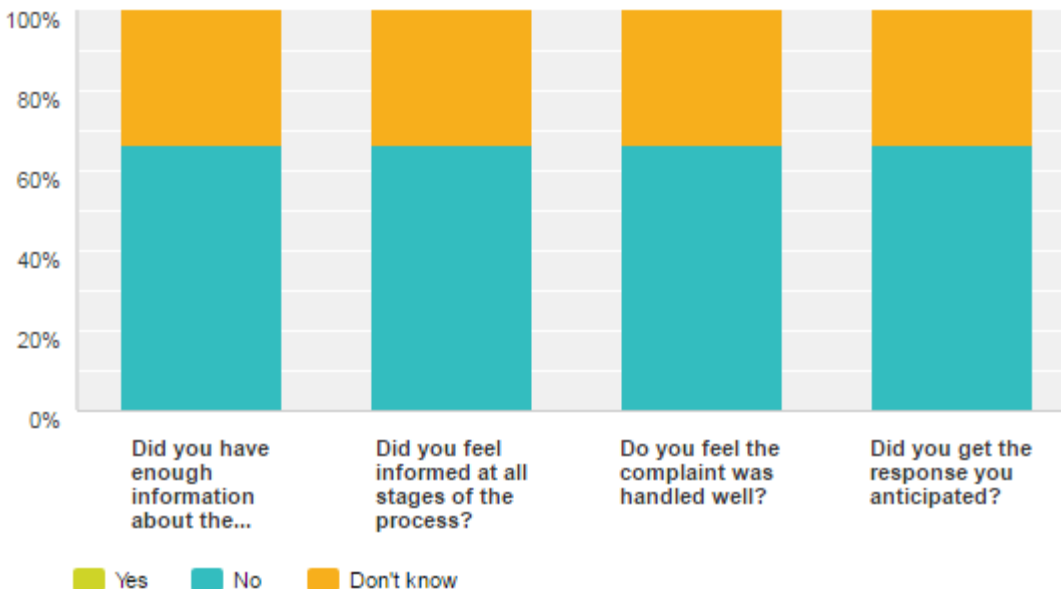
5.6 People’s experiences of making a complaint to the NHS in Brighton & Hove (6 respondents)

Participants who responded with a ‘yes’ to the above question (6 people) were asked, ‘Please tell us about your experience of making a complaint to the NHS in Brighton & Hove:

- Did you have enough information about the process?
- Did you feel informed at all stages of the process?
- Do you feel the complaint was handled well?
- Did you get the response you anticipated?’

To each question, they could respond ‘Yes’, ‘No’ or ‘Don’t know.’

No respondents responded with a Yes to any of the four questions. For each question, 67% (4) responded with ‘No’ and 33% (2) responded with a ‘Don’t know.’



Four people left a comment when invited to do so. One person felt they had been penalised for making a complaint:

“ I was discharged from the mental health service as a result of my complaint!”

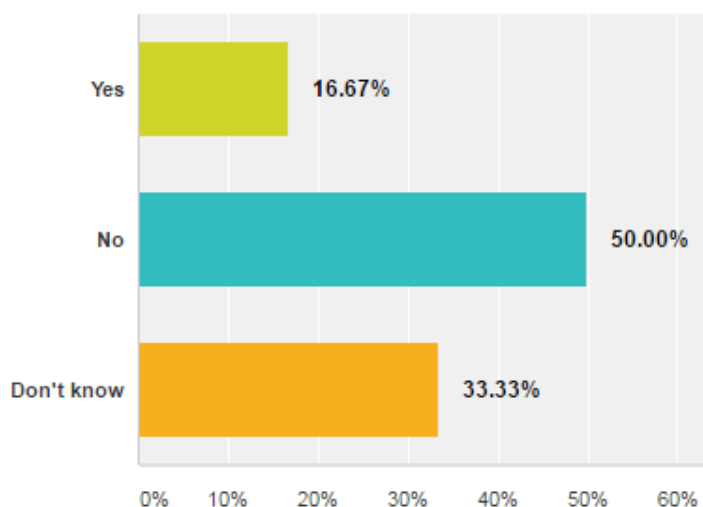
Another commenter felt ‘out of the loop’ during the process and seemed uncertain of the value of making a complaint:

“ I found a massive lack of info surrounding the process, what it entailed and what will/might happen after my complaint was made. Materials are never offered in alternative formats and I always feel slightly awkward about asking about that kind of thing... They weren't the best at keeping my carer and I informed but it could have been better, letters were sent to recognise my complaint and then a summary of what was going to happen as a result of xyz... But not really any contact in between which made the process very difficult, I felt very out of the loop. Unfortunately most complaints have been simply resolved with an apology (which is great but...) What about measuring learning outcomes? Small changes that could be implemented to improve efficiency of service and not comprise patient care? When ideas have been suggested and completely ignored it really makes you wonder why you've bothered :(“

5.7 Things that went well in relation to making a complaint to the NHS in Brighton & Hove

(6 respondents)

Respondents who had experience of making a complaint (6) were asked, ‘Was there anything that you feel worked well in relation to your NHS complaint?’



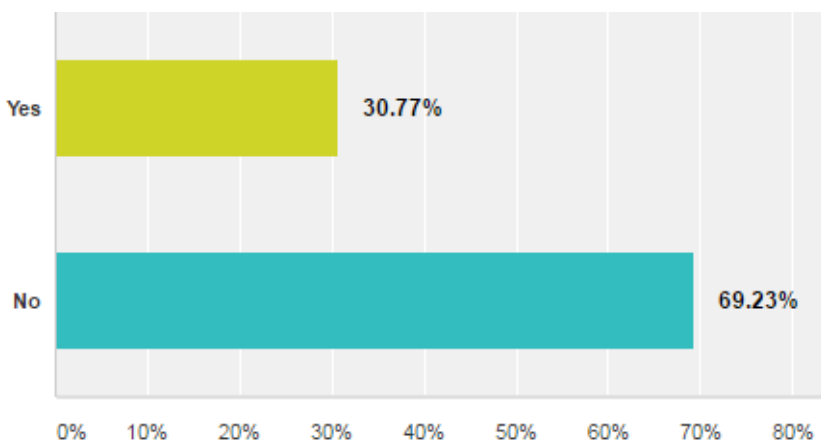
50% (3) of respondents to this question said that there was not anything that they felt had worked well.

33% (2) people said they did not know.

17% (1) said that the 'Friendliness and welcoming attitude of telephone staff was great.'

5.8 Awareness of NHS Independent Complaints and Advocacy Service (ICAS) (39 respondents)

Survey participants were asked: 'Did you know that there is an independent service (NHS Independent Complaints and Advocacy Service [ICAS]) that provides advice and information on making a complaint about NHS services, and which will provide a trained advocate to help you make a complaint?'

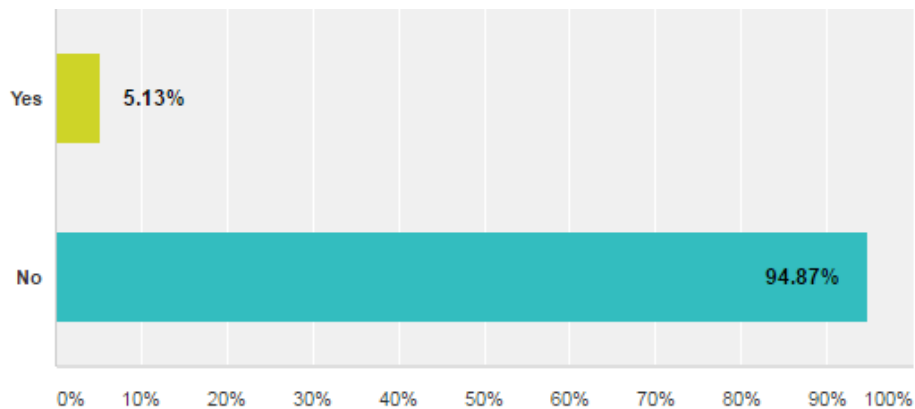


39 people responded to this question, of whom 31% (12) were aware of ICAS.

The remaining 69% (27) had not heard of ICAS.

5.9 Use of ICAS in Brighton & Hove (39 respondents)

Survey respondents were asked 'Have you used ICAS in Brighton?' Of the 39 respondents, 5% (2) said that they had, and 95% (37) had not used ICAS.



Of the 39 respondents to this question, 5% (2) had used ICAS and the remaining 95% (37) had not used ICAS.

The two participants who had used ICAS were invited to comment on their experience. One felt that ICAS had not helped to advance their complaint:

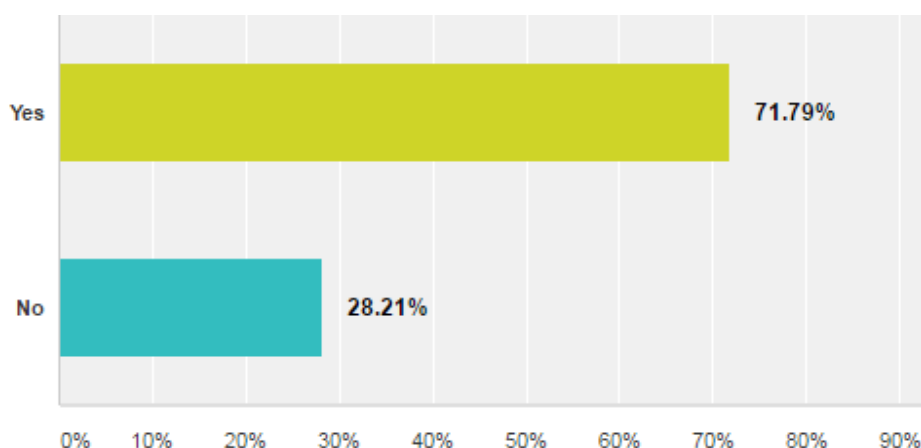
“ They were pretty useless to be honest, it didn't really help my complaints experiences or give any power to my complaint. I still got a crappy fobbed off answer to my complaint.”

The second respondent was unhappy with the service but did not offer an explanation.

“ Worst complaints service I have used.”

5.10 Awareness of the Brighton & Hove Patient Advice and Liaison Service (PALS) (39 respondents)

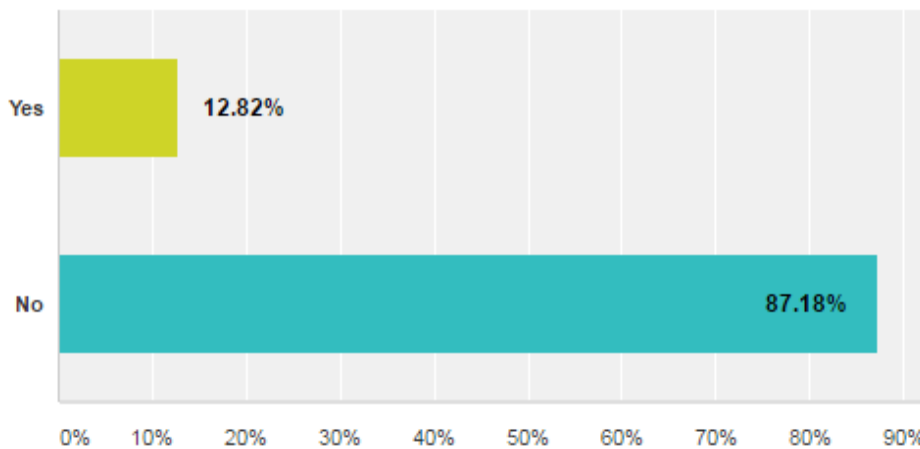
Participants were asked ‘Have you heard about the Brighton & Hove Patient Advice and Liaison Service (PALS) that can listen to any concerns you may have about care in local hospitals, and can quickly help to resolve them?’



39 people responded to this question, of whom 72% (28) were aware of PALS. The remaining 28% (11) had not heard of PALS.

5.11 Use of the Brighton & Hove Patient Advice and Liaison Service (PALS) (39 respondents)

Survey respondents were asked 'Have you ever used PALS in Brighton & Hove?'



Of the 39 respondents to this question, 13% (5) had used PALS and the remaining 87% (34) had not used PALS.

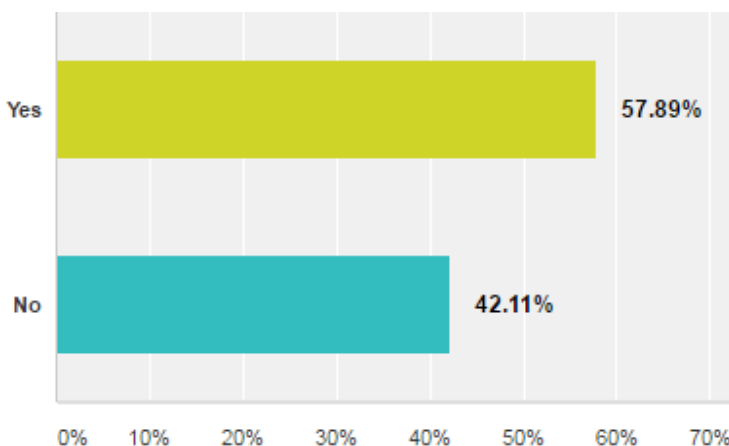
The five participants who had used PALS were invited to comment on their experience; four participants did so. One had a positive experience with a swift response, and another felt that PALS were helpful and helped resolve problems in a mostly impartial fashion. One person received the contact number they asked for but said the service was “not reassuring or sympathetic.”

A different person did not feel listened to by the service:

“They were pretty useless as they made some 'suggestions' which I had already tried. I really felt that no-one really listened to me properly or took my concerns seriously.”

5.12 Awareness of Healthwatch Brighton and Hove (38 respondents)

Survey participants were asked: 'Have you heard of Healthwatch Brighton and Hove? Healthwatch listens to your views and concerns about health and social care services in the city, and uses your views to influence commissioners and providers to improve services.'



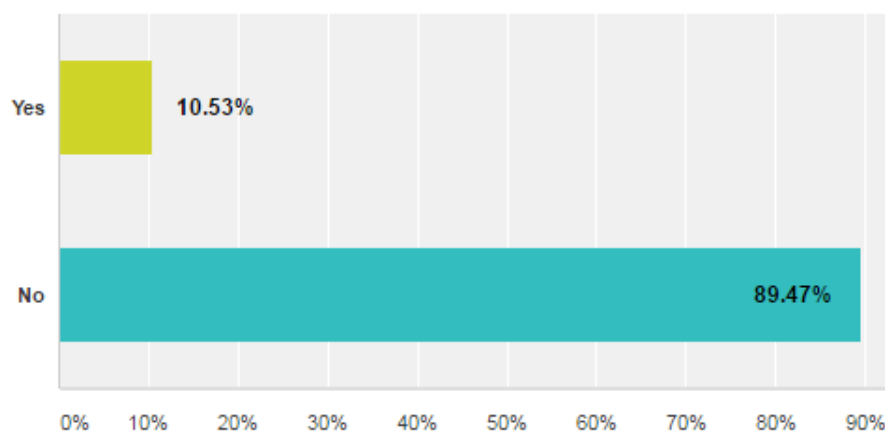
Of the 38 respondents to this question, 58% (22) had heard of Healthwatch and the remaining 42% (16) had not heard of Healthwatch.

Given the opportunity to comment, one participant was aware of Pulse, Healthwatch's online feedback centre. A second participant remarked that:

“ Healthwatch volunteers are largely not very helpful.”

5.13 Experience of using Healthwatch Brighton and Hove (38 respondents)

Participants were asked: *'Have you ever contacted Healthwatch to give feedback or seek advice on making a complaint?'*



11% (4) had used Healthwatch and the remaining 89% (34) had not used Healthwatch.

Of the four people who had used Healthwatch, two commented on the experience, one found the service very helpful.

A second participant found that:

“ They didn't really help. I went to PALS, Healthwatch and ICAS and none of them offered me anything extra than what I could already do myself i.e. write a complaint letter and send it. When I wasn't being listened to no one really helped me.”

5.14 Promoting the NHS complaints process and support agencies (38 respondents)

Participants were asked *'Which of the following would help to promote the formal NHS complaints process/PALS/ICAS/Healthwatch to LGBT people in Brighton & Hove, or make them more accessible?'*

An 84% (32) majority of respondents wanting to see posters about complaints processes displayed in healthcare settings. The second highest percentage of respondents, 66% (25) would like local LGBT magazines to carry articles about complaints processes, and 63% (24) would like LGBT websites to promote information about complaints processes.

Participants also wanted to see information on social media (58%, n22), in local print media (47%, n18) or on other, general websites (47%, n18). 39% (14) would like to hear announcements on LGBT radio programmes, and 24% (9) would like announcements on general radio/TV programmes. 32% (12)

would like to hear information presented at health or community group meetings that they already attend.

Answer Choices	Responses
Posters in health settings e.g. hospitals and GP Surgeries	84.21% 32
Articles in local LGBT magazines	65.79% 25
Websites (LGBT)	63.16% 24
Social media e.g. Facebook adverts	57.89% 22
Articles in local papers or magazines (general)	47.37% 18
Websites (general)	47.37% 18
Announcements on LGBT radio programmes	39.47% 15
Via health or community group meetings I already attend	31.58% 12
Announcements on the radio or television (general)	23.68% 9
Other (please specify) Responses	5.26% 2

Two participants marked 'Other' and went on to specify what they would find helpful. The first person felt that the local LGBTQ community may not have confidence in the NHS complaints process:

“Evidence that it works and that it is managed and run by professionals with high standards. A statement from local MPs perhaps, or a statement from leading LGBTQ figures in Brighton and Hove itself. There is no reason to trust the NHS complaints process for no reason if they have shown no evidence of structural and long-term support and understanding of the LGBTQ community in Brighton and Hove. The NHS in Brighton and Hove is known for treating LGBTQ staff and patients poorly.”

The second person suggested post-appointment follow-up via letters, text messages or emails.

5.15 Preferred methods for making a complaint or providing feedback (38 respondents)

Participants were asked, 'If you were unhappy with your care (or someone else's care), or would like to suggest ways to improve local health services, how would you like to do this? Please select all that apply.'

A 58% (22) majority of respondents preferred to speak to someone in charge of the service at the time or soon afterwards. A slightly smaller cohort of 55% (21) would access the NHS complaints process. 45% (17) of respondents would seek help from PALS in making a complaint while 42% (16) would prefer to offer feedback anonymously. 37% (14) would access help from Healthwatch and 37% (14) would use an online forum. 29% (7) would access support from ICAS, and 21% (8) would ask a community worker to gather their views with those of others and feed back to the service. 11% (4) would ask a family member or friend to feed back to the service for them.

Answer Choices ▼	Responses ▼
▼ Speak to someone in charge of the service at the time or soon afterwards	57.89% 22
▼ Make a complaint through the NHS complaints process	55.26% 21
▼ Access support from PALS	44.74% 17
▼ Give feedback anonymously (e.g. a comments card, or a form with a freepost address)	42.11% 16
▼ Access support from Healthwatch	36.84% 14
▼ Feed back using an online forum	36.84% 14
▼ Access support from ICAS	28.95% 11
▼ Ask a community worker to gather your views with those of others and feed back to the service	21.05% 8
▼ Ask a family member or friend to feed back to the service for you	10.53% 4

Invited to comment, four people did so. One person would use their LGBT advocate, while another would only make a complaint if other options had been unsatisfactory.

Another respondent would take steps not offered in the survey:

“ Speak to the press, write to my MP, let other people on LGBTQ forums know which areas to avoid so they don't suffer too.”

One commenter would prefer to complain without writing a great deal:

“ Via app, through technology or written template form that requires very little writing (mainly multiple choice) writing is very tiring, difficult and I struggle lots in this area. Services forget that many people communicate in different ways, and being aware of this helps massively 😊; applying this knowledge to materials provided would benefit many.”

5.16 Barriers to accessing the NHS complaints process and support agencies (38 respondents)

Participants were asked, ‘Are there any barriers that would prevent or discourage you from using the formal NHS complaints process/PALS/ICAS/Healthwatch?’

	Yes (1)	No (2)	Don't know (3)	Total	Weighted Average
Formal NHS complaints process	36.84% 14	47.37% 18	15.79% 6	38	1.79
PALS	24.32% 9	59.46% 22	16.22% 6	37	1.92
ICAS	24.32% 9	54.05% 20	21.62% 8	37	1.97
Healthwatch	23.68% 9	57.89% 22	18.42% 7	38	1.95

Where participants felt there were barriers, the highest percentage (37%, 14) felt that they existed in relation to the formal NHS complaints process. 24% (9) felt that barriers existed in relation to accessing PALS, ICAS and Healthwatch.

Invited to comment the nature of the barriers they felt existed, 13 participants did so. One person was concerned about clinicians' attitudes, while another lacked confidence in the integrity and professionalism of the NHS in Brighton & Hove. A third person felt that there is a 'protect yourself' attitude to the NHS, with internal cultural and political issues that affect complaint processes.

Three participants implied that LGBTQ people's concerns might not be taken seriously or might be ignored, including:

“ They maybe ignore my complaint because I am gay and HIV positive.”

“ It's hard to believe that anybody working for an organisation would act on complaints from LGBT people, even in Brighton and Hove.”

Another respondent felt that services are not aware enough of LGBTQ identities, and need to be more accessible:

“ None of them are really clued up on non-binary identities. Also there is a lack of awareness about accessibility, for example they all want to speak to you on the phone but I have a hearing impairment and they are reluctant to do email. General need for LGBTQI training.”

One person felt that a negative experience with PALS and Healthwatch affected their likelihood of using either service:

“ I have had previous experience of using PALS in a different area with very poor results so I don't have any confidence in the service. I have used Healthwatch previously for advice and to alert them about barriers to GP access for vulnerable people but didn't find it to be particularly useful and didn't get much from it so I would be reluctant to go through their service again.”

Other barriers participants identified included being worried about how to take things forward, being afraid of confrontation and concerns about emotional and physical stamina.

6. KEY FINDINGS

Awareness of NHS complaints processes and support agencies

The online survey suggested a fairly high level of awareness (69%) about how to use the NHS complaints process, and a fairly high level of willingness (77%) to make a complaint if necessary. However, less than a third of respondents said that they knew how to make a complaint if needed.

Of the complaints support agencies, PALS (72%) was the one that the highest number of participants was aware of, followed by Healthwatch (58%), with the least familiar being ICAS (30%). The level of use of these services follows the same order, with PALS having been used by 13% of respondents, Healthwatch by 11% and ICAS by 5%.

Experiences of making complaints to the NHS

15% of survey respondents had made a complaint to the NHS in Brighton & Hove. 0% (0) of survey respondents who had made a complaint/complaints felt that they were well informed about the process, felt they were kept informed during the process, felt the complaint was handled well or that they got the outcome they expected. Only one out of six survey participants (17%) who had made a complaint to the NHS felt that anything had worked well in relation to the complaint.

Comments made in the survey about participants' experiences with making a complaint highlighted a lack of information during complaints procedures, long timescales and, in one person's case, being discharged from a mental health service as a result of making a complaint.

The case study participant who made a complaint to the NHS also had a negative experience when her complaint letter was never acknowledged or responded to.

Experiences of using PALS, Healthwatch and ICAS

The two survey participants who had used ICAS were both unhappy with the service. Of the four people who commented in the survey on their experience with PALS, three found the service helpful but two commented negatively on the tone of the support. Of the two survey respondents who had used Healthwatch, one found the service very helpful and the other said they had not felt helped.

One case study interviewee used all three support agencies and did not find any of them particularly helpful. They all offered her information about the NHS complaints process and signposted to each other, but none offered her support with actually making the complaint.

Barriers to using the NHS complaints process and support agencies

Survey participants perceived more barriers to using the NHS complaints process (37%) than to using PALS, ICAS and Healthwatch (each 9%). Key barriers identified by survey participants and case study interviewees are:

- not knowing how to make a complaint
- having a lack of confidence in NHS's ability to handle the complaint impartially and effectively
- concerns that LGBTQ community members' concerns will not be taken seriously
- concerns about retribution from the NHS

- prior negative experiences with the NHS complaints process or the support agencies
- lack of physical/mental/emotional energy
- access needs e.g. dyslexia

Encouraging more complaints

The majority of respondents would be most likely to make a complaint if they could have somebody at the NHS to talk to initially about the issue (59%) or access independent support with making a complaint (55%).

The need for independent support with making a complaint was also raised in two out of three case studies, but one person interviewed had found that while PALS, ICAS and Healthwatch shared information about how to make a complaint, none of them actually helped her to make a complaint. One of the case studies mentioned that if LGBTQ services offered general advocacy they would use that service to support them with making an NHS complaint.

Accessible information and processes

For just over half of survey respondents, having information about the complaints process in an accessible format would encourage them to make a complaint. This was borne out in one of the case studies too, where a person with dyslexia noted that alternatives to letter-writing would be useful.

Survey participants particularly want to see information about how to make a complaint in healthcare settings, in LGBTQ magazines and websites and via social media.

7. CONCLUSIONS

A significant proportion of LGBTQ community members engaged with are unaware of how to make a complaint about NHS services in Brighton & Hove. Over a third of community members have described barriers preventing them from wanting to make a complaint. Where community members have experience of making a complaint, whether directly using the NHS complaints process or using one of the support agencies, they report dissatisfaction with the process. Community members that we engaged with would like information about NHS complaints processes to be made available in a range of formats, media and settings.

8. RECOMMENDATIONS

These recommendations have been developed out of the findings of the online survey and the focus group. It is hoped that the following recommendations may act as a guide for the CCG:

1. Leaflets and posters about NHS complaints processes and PALS/Healthwatch/ICAS should be clearly displayed in hospitals, GP surgeries and other NHS settings
2. The CCG should work with LGBTQ partners in Brighton & Hove to promote NHS complaints information in LGBTQ magazines/websites/social media
3. The above avenues should also be used to provide clear and accessible ways for community members to provide feedback about PALS/ICAS/Healthwatch
4. Consideration should be given to a routine text follow-up being made to patients after appointments soliciting feedback, and including a phone number to speak to an independent service, and a YouTube video link about how to make a complaint
5. Consideration should be given to providing a central phone number that community members could call to discuss any potential complaint and receive information/signposting
6. Consideration should be given to developing an independent body to monitor NHS complaints and response times/outcomes, with penalties for failing targets such as replying to complaints
7. An LGBTQ-inclusive healthcare advocacy service should be considered that could help community members make complaints
8. LGBTQ awareness training should be provided to NHS staff across the board, and also to call handlers and advocates at PALS/ICAS/Healthwatch
9. Options to improve recording health appointments should be explored. This could enable complaints to be evidenced if necessary, as well as to support better recall of information if patients need this to support a complaint
10. The CCG should provide evidence of the efficacy of complaints processes and this should be communicated to LGBTQ communities.

Key Contacts

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