Switchboard

Connecting you to LGBTQ support

LGBTQ+ D/deaf and hard of hearing access to healthcare

ENGAGEMENT REPORT
SEPTEMBER 2018

Brighton & Hove City Council group has commissioned Switchboard (formerly 'Brighton and Hove LGBTQ Switchboard') to conduct a series of consultation and engagement activities with Brighton & Hove and Sussex-based lesbian, gay, bisexual, trans and queer (LGBTQ+) Deaf, deaf and hard of hearing communities in relation to healthcare inclusion and access. This engagement work will be used to inform how LGBTQ+ Deaf, deaf and hard of hearing people can be best supported; and to identify areas where improvements to patient experience can be made.

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

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Executive Summary

Brighton and Hove City Council commissioned Switchboard to engage the local D/deaf and hard of hearing[1] LGBTQ+ communities around inclusion needs and experiences when accessing healthcare. The engagement was carried out across July to September 2018 using online survey and one-to-one interview methods.

Summary of Key Findings

Lack of understanding/ awareness of D/deaf and HoH issues was reported as a leading barrier for 62% of respondents, and healthcare **professionals not being LGBTQ-aware or inclusive**, was experienced by half. **This rose to 100% for Deaf respondents.**

Low staff confidence addressing both LGBTQ+ (45%) and **D/deaf/HoH** (19%) issues was also reported as a key barrier to accessing healthcare.

More than **6 in 10** said **lack of understanding of D/deaf/HoH issues** was a barrier to accessing healthcare. This rose to **100%** for Deaf LGBTQ+ respondents

> "I'm not surprised healthcare professionals aren't confident to discuss LGBTQ issues. The message we get is 'not for discussion' and this is really harmful"

Nearly a third of respondents (30%) said they were afraid to disclose their sexual orientation or gender identity due to fears of homo/ bi/ trans-phobia and the same number said they had actually **experienced these forms of discrimination** from staff in the past.

> "I've […] been told that everything is as a result of being gay, and that it clearly caused my mental health problems"

Nearly half (43%) had experienced direct discrimination from hearing staff in response to being D/deaf or HoH, including forcing the suggestion of cochlear implants after this had been declined. **This rose to two in three for Deaf respondents.**

> "I do not attend locally any more due effect me with communication breakdown too many times in the past and I had no energy left to put it up again […] I always felt uncomfortable to attending the GP, Clinic, Hospital due of people look at me as a deaf and disabled and they talk about me I do not like I prefer respect"

[1] Abbreviated throughout as D/deaf/HoH

Heteronormativity, particularly the assumption that one is straight/ heterosexual, was experienced by 85% of respondents. Relatedly, more than a third of respondents (35%) had **experienced their partners not being recognised as such** by healthcare staff.

85% had experienced heteronormativity as a barrier and 100% of trans respondents had been mis-gendered by staff in a healthcare setting

> "I am completely comfortable with my sexual orientation and don't mind having to come out, I just wish I didn't have to, as in that the assumption is always that you are heterosexual. I never make that assumption, so maybe there could be more training around that?"

> "Presumption my next of kin is my female friend not wife. Presumption my wife is a carer"

100% of trans* respondents said they had experienced being mis-gendered (addressed with an incorrect name, pronoun, title or other gender indicator) by staff.

> "Assumption by people I am in contact with on the telephone that I am gender male, even after I have explained fully that I am transgendered female and do not wish to be addressed as 'Sir' or prefixed 'Mr'."

In much the same way that sexual orientation and gender were often assumed, many respondents **expressed frustration at their level of hearing and types of communication need being assumed**, leaving them frustrated with needing to strongly self-advocate to ensure clear communication or risk missing important information.

> "I was asked if I was HoH, it made the whole experience much safer and easier"

D/deaf/HoH-related healthcare barriers were reported more prevalently than LGBTQ+ specific issues, with 8 of the 10 'negative healthcare experiences' provided related to D/deaf related barriers, and only 2 to LGBTQ+ issues.

More than 4 in 10 said that other aspects of their identity – such as sexual orientation, gender, disability or race for example – were not taken into account due to them **being perceived first and foremost as a D/deaf or HoH person**

However, an understanding of the intersections of these and other experiences/ identities was considered key. Many respondents reported a tendency of some healthcare staff to reduce patients to one marginalised characteristic only, and ignore other aspects of identity and experience at the expense of this.

Nearly half (43%) said that other aspects of their identity – such as sexual orientation, gender, disability or race for example – were not taken into account due to them being perceived first and foremost as a D/deaf or HoH person, and that this was a barrier for them to accessing healthcare.

> "There seems to be a lack of belief that I can be both and that problems are either one or the other"
>
> "I don't notice about my sexual preference to them they do not ask me if I am a Gay or sexual choice! main mostly was focus on my deafness I have seen their barriers to me!!"

Deaf LGBTQ+ *respondents tended to indicate their* ***Deafness was more of a barrier to healthcare than their LGBTQ+ identity*** *while many other deaf and hard of hearing respondent* ***emphasised the need for both – and other – aspects of their experience to be taken into account***

Intersecting forms of marginalisation involving LGBTQ+, D/deaf/HoH and other aspects of identity, such as race and ethnicity, came through as a key theme. Trans respondents, in particular, highlighted the ways in which deaf communication barriers and a lack of LGBTQ+ awareness can collide:

> " I am more self-conscious/aware of my skin colour when accessing services"

Nearly 1 in 3 reported living with a mental health difficulty and/or a physical impairment of mobility issue, while 1 in 5 live with a long-term illness, highlighting even greater need for attention to health inclusion for this intersection of the community.

Engagement of the BSL-using Deaf LGBTQ+ community members was low, reportedly due to a lack of BSL translated clips to accompany the online survey. While 1-1 interviews with BSL interpretation were offered and promoted, no Deaf LGBTQ+ individuals chose this option, highlighting the need for further work around Deaf inclusion and engagement.

Barriers to communicating in appointments and with reception staff was an issue for more than half of respondents. Nearly a third had experienced difficulties resulting from a lack of available hearing loop, a third faced issues receiving test results and nearly a quarter said they had to make appointments in-person at the service location due to a lack of online or text-relay options.

> *"All too often a name is called out for the next person on the treatment list. The name may be an inappropriate name or title for the pre-op and non-op transgender patients. Their assumed new names do not normally appear on hospital records and the staff often call out that name against a background of piped music or other continuous noise. It often needs repeating loudly until the patient can be alerted. There is obvious embarrassment when responding, as a woman, to a call for 'Mr Jones', or as a man, to 'Miss Jones'."* – Survey respondent

Missing verbal cues for appointments while in the waiting room was a commonly reported issue.

> "Often the hearing person was showing annoyed to try get information from me, if I turn up without interpreter as some appointments that do not need interpreter like having a blood test that was all often caught their expression was showing rude and can see the body language changed if I said can you repeat to speak slowly as I am deaf "

> "once arrived clinic and Did wait, wait, wait, and wait then finally the person calling the name then walk off, I wasn't sure if it was me then again I feel embarrassed to ask if it is my name"

Two thirds of Deaf LGBTQ+ *respondents had experienced a* ***lack of BSL interpreter availability*** *for healthcare appointments*

2 in 3 BSL using Deaf respondents to the survey said lack of access to an in-person BSL interpreter for appointments was a barrier.

> "Resident doctor booking interpreter and then turning up 5 minutes prior to the end of the interpreter booking"

"More visibility [is needed] as I know Deaf LGBTQ+ people feel unheard, unseen and un-respected - probably due to ignorance and the ignorance of the intersectionality of multiple issues doesn't help." – Survey respondent

4 in 10 reported a lack of LGBTQ inclusive resources to be an issue, and several respondents commented on issues of resources not being D/deaf/HoH inclusive, with some medical jargon providing a particular barrier for members of the BSL Deaf community

> "all was words everywhere I had to read and think again and again to taking the concept the words means mostly do use medical jargons all the times!!"

Greater participation and representation of D/deaf/HoH LGBTQ+ communities in healthcare provision was identified as a key step to addressing these challenges and improving health inclusion.

> "A double minority group, we need to be invited to patient participation groups"

Executive Summary of Recommendations

A more detailed version of the recommendations can be found at the end of the report.

Brighton & Hove City Council and Brighton & Hove CCG

1. **LGBTQ+ and D/deaf and hard of hearing awareness training for frontline healthcare staff**, targeting raising issues relating to individual intersectional points of marginalisation; challenging stigma, stereotypes and discriminatory practices, particularly around heteronormativity and cisnormativity.
2. **Provide online booking for appointments and receiving test results, e**nsuring that online systems properly reflect the person's correct name, pronouns and titles (following on from the April 2018 Monitoring Engagement Report Recommendations)
3. **Ensure Deaf inclusion is built into service planning, including ring-fencing budget for BSL interpretation,** as part of Brighton & Hove City Council's commitments under pledges 1 and 2 of the British Deaf Association's BSL Charter[2].
4. **Make intersectional inclusion a priority in patient participation groups,** particularly with regard to including members of the Deaf, deaf and hard of hearing and LGBTQ+ communities.
5. **Offer visual cues for appointments and information in waiting areas** (e.g. screens showing patient name calls) and ensure that patient **information is accurate and sensitive to trans patients, with regard to correct name, titles and pronouns.**

Switchboard

1. **Secure Deaf-awareness and introductory BSL training** for frontline staff to ensure a good level of D/deaf and HoH awareness and competence
2. **Seek to improve LGBTQ+ Deaf inclusion and representation at Switchboard as part of the creation of a new Community Steering Group**
3. **Continue to develop relationships with Deaf organisations**, to improve signposting relationships and inform future engagement.

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[2] Brighton and Hove City Council signed the British Deaf Association's British Sign Language (BSL) Charter in 2017, committing to five pledges:

1. Consult formally and informally with the local Deaf community on a regular basis
2. Ensure access for Deaf people to information and services
3. Support Deaf children and families
4. Ensure staff working with Deaf people can communicate effectively using British Sign Language
5. Promote learning and high quality teaching of British Sign Language

Introduction

Brighton and Hove City Council commissioned Switchboard to engage the local D/deaf and hard of hearing[3] LGBTQ+[4] communities around inclusion needs and experiences when accessing healthcare. The engagement was carried out across July to September 2018 using online survey and one-to-one interview methods.

> *"[Being LGBTQ and deaf] can be no big deal, or it can be a double discrimination."*
>
> – Survey respondent

As a group of 'multiple minority' status, D/deaf/HoH LGBTQ+ communities face multiple and intersecting challenges when trying to access 'mainstream' services, where being hearing and cis-heterosexual[5] are explicitly or unconsciously considered the 'norm'. Reflecting this, a strong finding throughout indicated a need for an intersectional approach, with many respondents reporting a sense of their LGBTQ+ identity, D/deaf/HoH experience and other characteristics being split apart in the healthcare system, without seeing how these intersect to form unique experiences and barriers to accessing healthcare.

A number of barriers to accessing healthcare were highlighted through the engagement. Some of these were indicative of a need for further training, such as the need for greater awareness, understanding and confidence around LGBTQ+ and D/deaf/HoH issues, while others called for structural adjustments to more meaningfully support inclusion, such as factoring BSL interpretation and translation provision into project, service and resource planning, and increasing Deaf LGBTQ+ visibility in resources.

Speaking to the difficult history of Deaf LGBTQ+ health inclusion in Brighton and Hove, Brighton-based presenter on Deaf and LGBTQ+ identity, Iain Poplett (date unknown) writes that, during the 1990's HIV/AIDS crisis, lack of communication with LGBTQ+ Deaf individuals with support and care organisations was "a big problem", with "only Deaf based national organisations, AIDS AHEAD & Deaf MESMAC, [providing] the support." He continues that, although the situation has since improved, health inclusion is still an issue for this community, particularly in terms of sexual health inclusion.

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[3] Abbreviated throughout as D/deaf/HoH

[4] LGBTQ+ refers to lesbian, gay, bisexual, trans*, queer and questioning and other non-cis-heterosexual sexual orientations and genders

[5] 'Cis-heterosexual' refers to the majority whose gender matches the gender they were assigned at birth and who also identify as heterosexual/ straight

As such, this engagement topic provides an important opportunity to learn more about the current, specific experiences of this intersectional community when attempting to access healthcare, and offers recommendations for how the existing challenges can be addressed.

Methodology

Survey

The survey was offered in paper and online (via SurveyMonkey) formats.

In discussion with the Deaf cultural outreach charity for Sussex, DeafCOG, Switchboard learned that the survey we had created had limited accessibility for some parts of the BSL Deaf communities. This is because written English is a second language to BSL for many. DeafCOG advised we therefore include BSL interpreted clips with the survey. However, unfortunately, due to the organsation's translator being unavailable, this was not possible. Confiring this, a Deaf survey respondent gave feedback that the survey, without BSL clips, wasn't accessible enough for many Deaf BSL community members.

As a compromise, we carefully edited the survey to plain English, and emphasised the option of one-to-one BSL interpreted interviews for BSL Deaf individuals. We acknowledged and apologised for the lack of BSL clips on the first page of the survey, and invited interested individuals using BSL to instead contact a member of the HIP team to arrange an interview with a BSL interpreter. We confirmed that we would provide the interpreter and that travel expenses would be covered.

1-to-1 Interviews

Promoted the interview opportunities via a paper flier/poster and online engagement (email and social media campaigns), as well as at the end of the survey. As the survey was not found to be Deaf inclusive enough, due to a lack of BSL clips, we emphasised the 1-1 interview option for the Deaf BSL community.

Explored the possibility of using Sign-Live, but found the cost to be prohibitive.

Engagement strategy

Engagement took place online and via in-person events. In addition to an email and social media campaign to our Switchboard newsletter list, and followers via facebook

and twitter, engagement took place via a range of other online and in-person channels and events, including:

- A member of the LGBT Community Safety Forum, with whom we linked in for this engagement, attended an LGBT Deaf Meet-up at the Amsterdam Bar in Brighton, where she discussed the engagement and distributed flyers about the survey and interviews.
- Via the 'Sussex Deaf LGBT' Facebook Group https://www.facebook.com/BrightonDeafLGBT/?hc_ref=ARQToMBK86Y6_0XA0_6vFWZgdpe3cu2S0BcL0x285KFfKG7pOF_M7ztu2zxti7qNpl0&fref=nf
- DeafCOG promoted the surveys and interviews via their facebook and twitter accounts
- We also circulated the survey throughout the Switchboard staff and volunteer team and their networks related to their respective projects, including Older People, Disabilities, Volunteers, and Dementia.
- Additionally we circulated the call-out through the CommunityWorks email list, and reached out to a number of organisations directly to circulate the engagement through their networks.

The regular meet-up and information event 'Our Space', organised by DeafCOG, did unfortunately not coincide with the timeframe of the consultation. The meetings, which alternate between venues in Eastbourne and Brighton, would have been a positive engagement opportunity, but regular attendees were still reached via DeafCOG's social media platforms and newsletter.

Online Survey

Overview and Method

The online survey was launched via SurveyMonkey and was live for four weeks across August and September 2018.

The survey contained a combination of quantitative and qualitative questions, designed to give both an overview of the general incidence of certain kinds of experiences, and more detailed insight.

35 individuals responded to the survey, of which 30 provided valid responses which passed a screening question. The screening question filtered out individuals who did not meet the following criteria:

- Work, study, live or socialise in Brighton and Hove
- LGBTQ+ identified
- Deaf, deaf or hard of hearing

Care was taken to write the survey in plain English. A pre-amble explained the purpose of the consultation and provided details of a contact for further information.

Following consultation with DeafCOG, we acknowledged the lack of BSL clip-interpretation in the survey, and offered 1-1 interviews with a BSL interpreter instead.

There was a short demographics equalities monitoring survey at the end, followed by a ‘feedback and comments’ free text field for respondents to provide feedback on the survey itself.

Survey Demographics

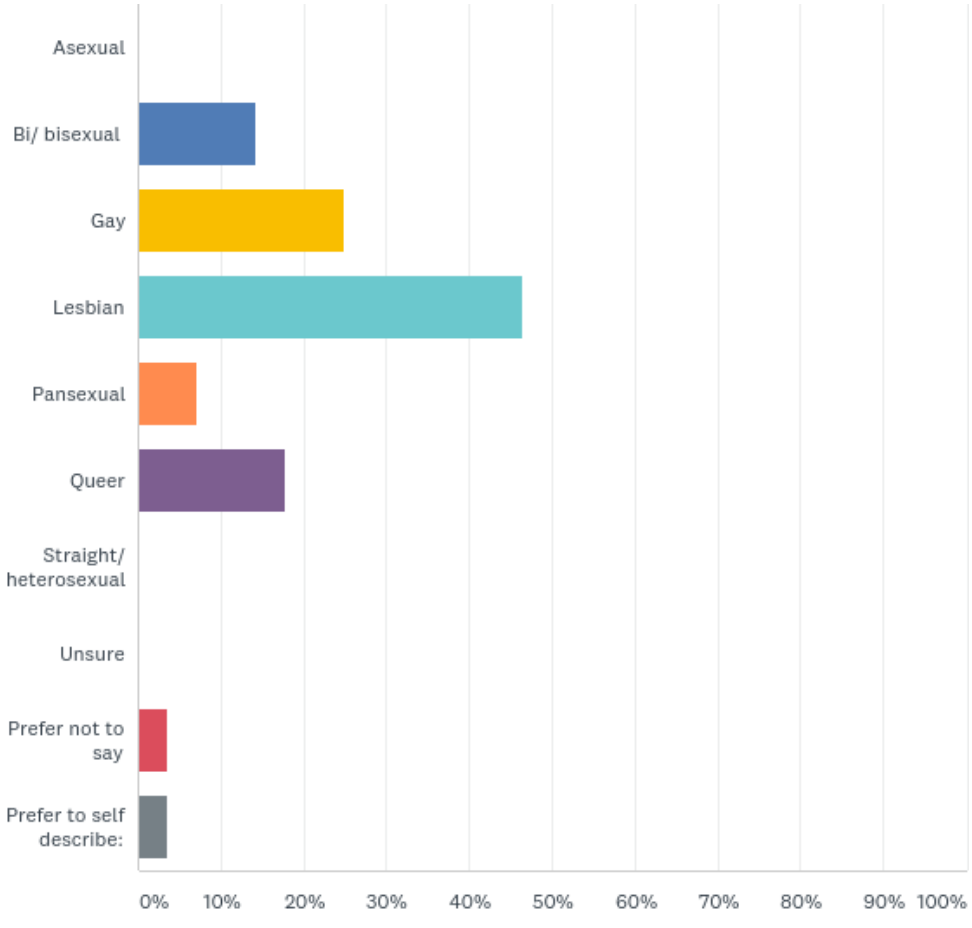
We asked questions about sexual orientation, gender, trans and intersex status at the beginning of the survey to ensure a higher likelihood of this crucial information being captured. The remainder of the equalities monitoring questions were asked at the end of the survey.

This decision was taken because a full equalities monitoring survey at the beginning often leads individuals to disengage, but many will choose to skip equalities monitoring questionnaires at the end as they are perceived as time consuming and less important.

This seemed to be an effective strategy, as around 8 more respondents provided information about these characteristics than went on to complete the equalities monitoring questionnaire.

Sexual Orientation

We asked respondents "**How do you describe your sexual orientation?" (28 answers)**



The largest proportion of respondents identified as lesbian, at 46% (13), followed by gay at 14% (7). 5 (18%) identified as queer, and 4 (14%) as bisexual. 2 (7%) identified as pansexual, and none identified as asexual, straight or unsure.

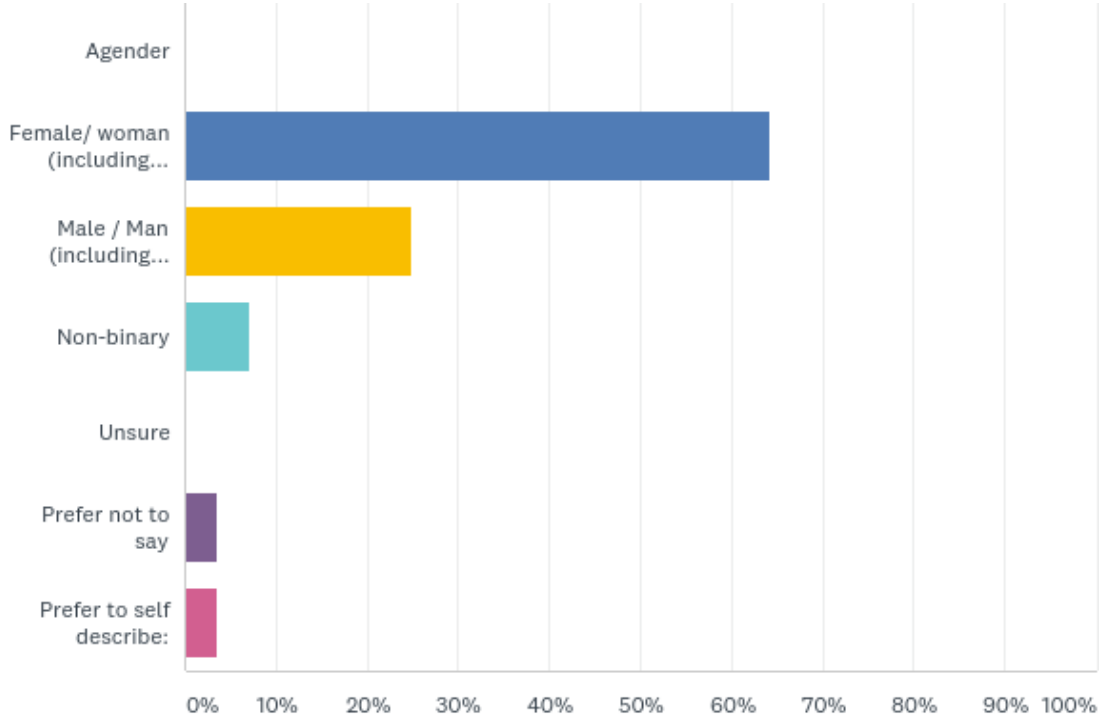
One chose prefer not to answer, and chose to self-describe but did not provide an answer.

Gender

We asked respondents "**How do you describe your gender?" (28 answers)**

The majority of respondents were women (64%, 18), followed by men at 25% (7) and 2 were non-binary. None identified as agender or said 'unsure'.

One chose prefer not to answer, and chose to self describe but did not provide an answer.

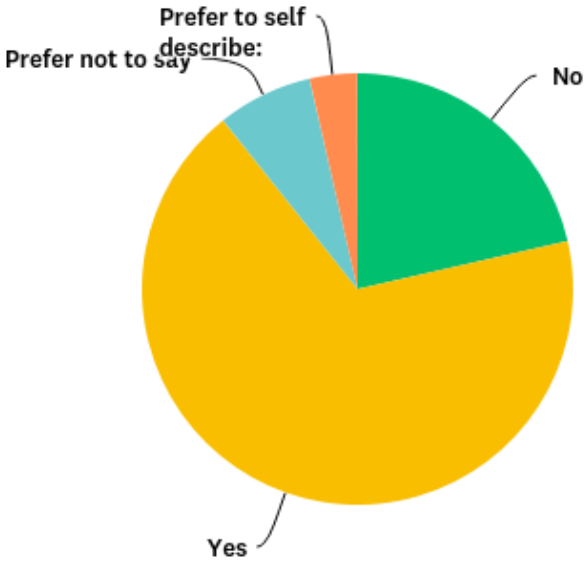


Trans status

We asked respondents "**Is your gender the same as the gender you were assigned at birth?" (28 answers)**

68% (19) of respondents said their gender matched the gender they were assigned at birth, while 6 (21%) said 'no' to this question, indicating they are somewhere on the trans and/or non-binary spectrum, or have a trans history.

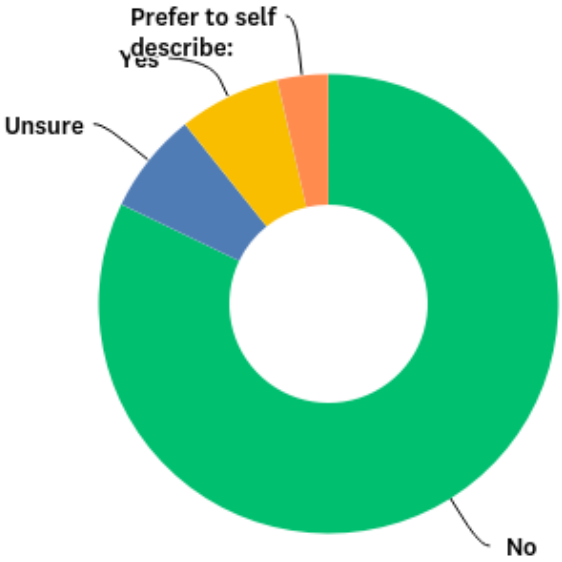
Two said ‘prefer not to say’ and one chose to self-describe but did not provide an answer



Intersex status

We asked respondents “**Do you have an intersex variation? Intersex is a term for people born with atypical physical sex characteristics. There are many different intersex traits or variations.” (28 answers)**

2 (7%) each said they were intersex or unsure, while 82% said ‘no’. One chose to self-describe but did not provide an answer

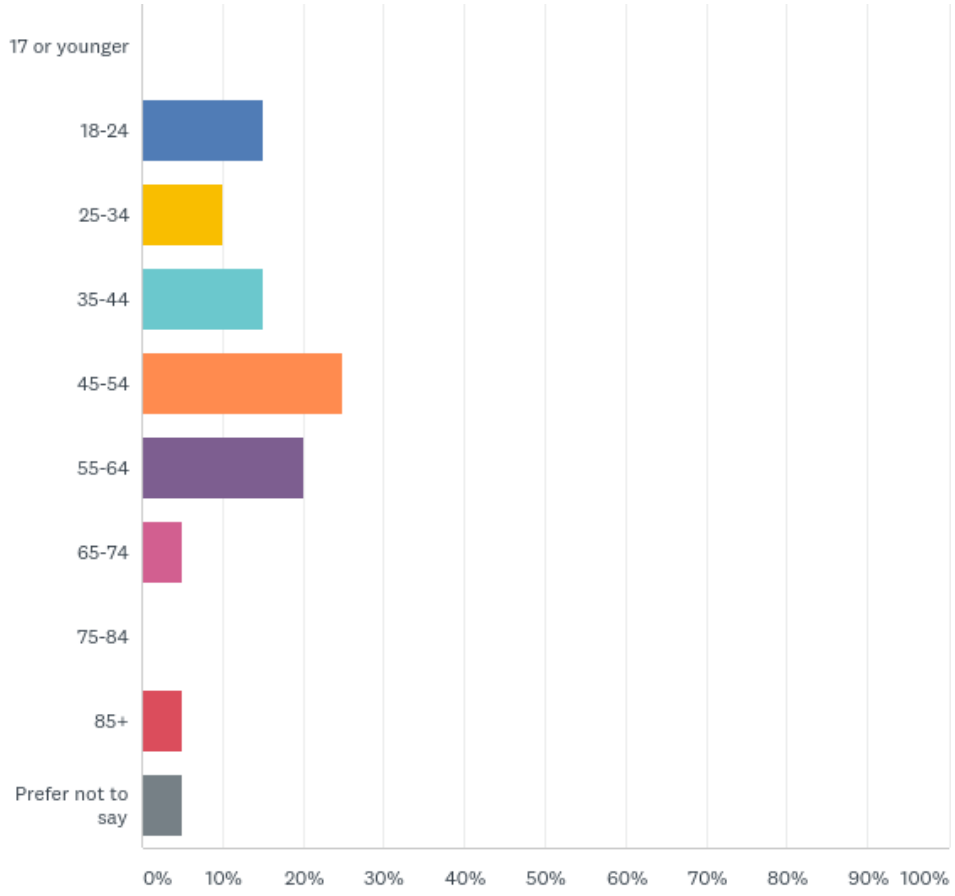


Age

We asked respondents "**What was your age at your last birthday?" (20 answers)**

The age of respondents was distributed as follows:

ANSWER CHOICES	RESPONSES	
17 or younger	0.00%	0
18-24	15.00%	3
25-34	10.00%	2
35-44	15.00%	3
45-54	25.00%	5
55-64	20.00%	4
65-74	5.00%	1
75-84	0.00%	0
85+	5.00%	1
Prefer not to say	5.00%	1
TOTAL		20

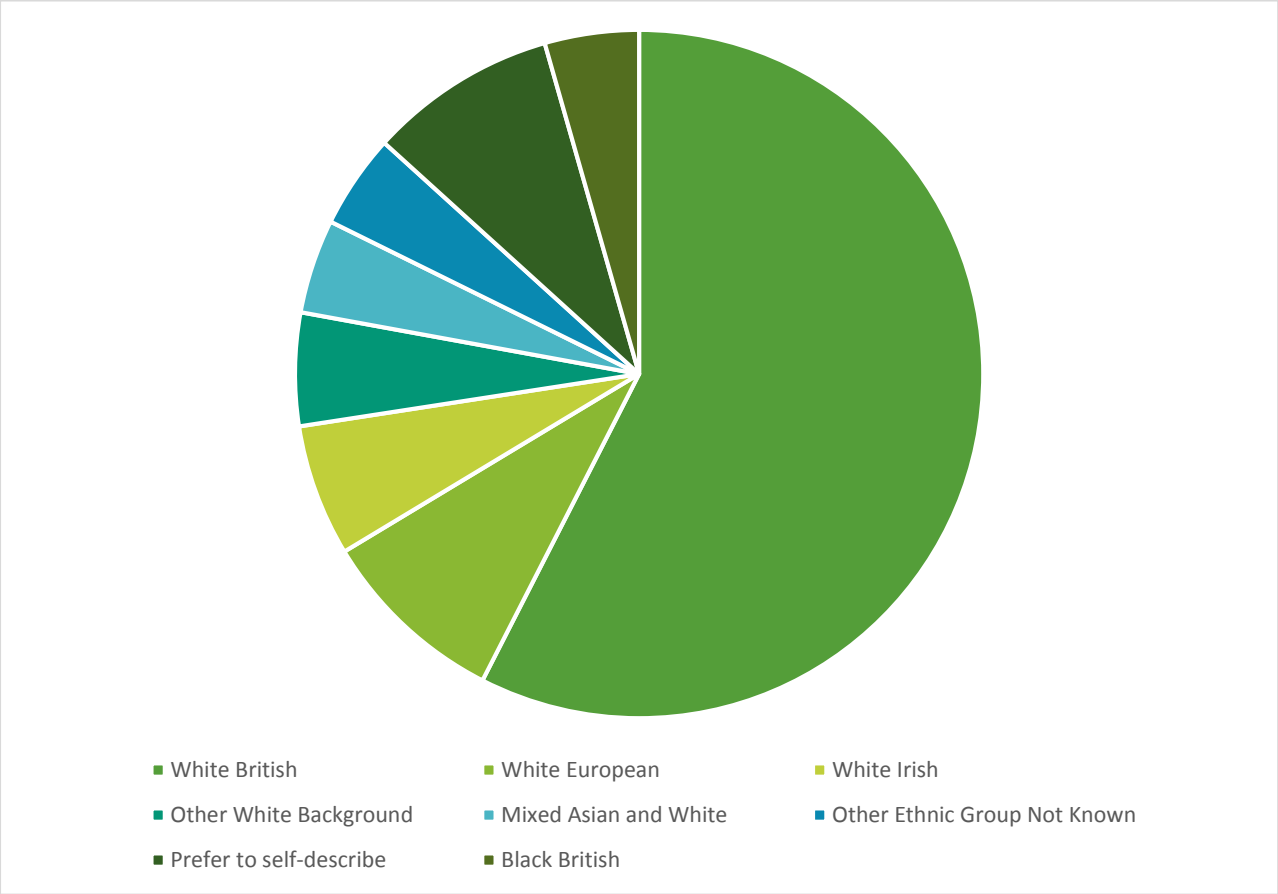


Ethnic Origin

We asked respondents "**How do you describe your race/ethnic origin?" (20 answers)**

13 (65%) identified as White British. 2 (10%) were White European, 1 (5%) White Irish and 1 (5%) Other white background. 1 (5%) identified as Black British (other black background) and 1 (5%) as Mixed Asian and White. 1 (5%) said other ethnic group not known. 2 (10%) chose 'prefer to self-describe' and said:

- *Irish English White*
- *European African*



Faith, religion and spirituality

We asked respondents "**If you have a religion, faith, or spirituality, how would you describe it?" (20 answers)**

The faith, religious and spiritual affiliation of respondents was distributed as follows:

ANSWER CHOICES	RESPONSES	
Atheist / No Religion	65.00%	13
Buddhist	0.00%	0
Christian	15.00%	3
Hindu	0.00%	0
Jewish	0.00%	0
Muslim	0.00%	0
Sikh	0.00%	0
Spiritual	10.00%	2
Prefer not to say	5.00%	1
Prefer to self describe:	5.00%	1
TOTAL		20

One chose to self-describe and stated “heathen”

Disability

We asked respondents “**Do you live with a health condition, impairment, learning difference, or neurodivergence that shapes your day to day activities?” (20 answers)**

The responses were distributed as follows:

ANSWER CHOICES	RESPONSES	
No known health condition, impairment, learning difference, or neurodivergence	0.00%	0
Long-term illness or health condition (e.g. cancer, chronic heart disease, diabetes, epilepsy, HIV)	20.00%	4
Mental health difficulty (e.g. addiction, anxiety, depression, eating disorders)	30.00%	6
Physical impairment or mobility issues (e.g. difficulty using your arms, using a wheelchair)	30.00%	6
Neurodivergence, meaning your brain or mind works very differently from social views of what is 'normal' (e.g. AD(H)D, Asperger's syndrome/ other autistic spectrum condition, bipolar, dyscalculia, dyslexia, dyspraxia, Tourette syndrome)	20.00%	4
Social or communication condition (e.g. a speech and language impairment, Asperger's syndrome/ other autistic spectrum condition)	15.00%	3
Specific learning difficulty (SpLD) (e.g. AD(H)D, dyscalculia, dyslexia, dyspraxia)	15.00%	3
Blind or visual impairment that can't be fixed with glasses	5.00%	1
D/deaf or hard of hearing	90.00%	18
Prefer not to say	0.00%	0
Prefer to self describe:	15.00%	3
Total Respondents: 20		

Of the 3 who selected ‘prefer to self describe’ only 1 provided a response, stating: “mobility sometimes - cellulitis / lymphedema - long term illness”

It is of interest that only 90% of respondents selected ‘D/deaf or hard of hearing’. This may be in part due to preferring other terms (such as ‘hearing impaired’ as provided earlier) or feeling that their experience was not significant enough to warrant this (as in the person who earlier responded ‘a bit deaf’).

Survey Findings

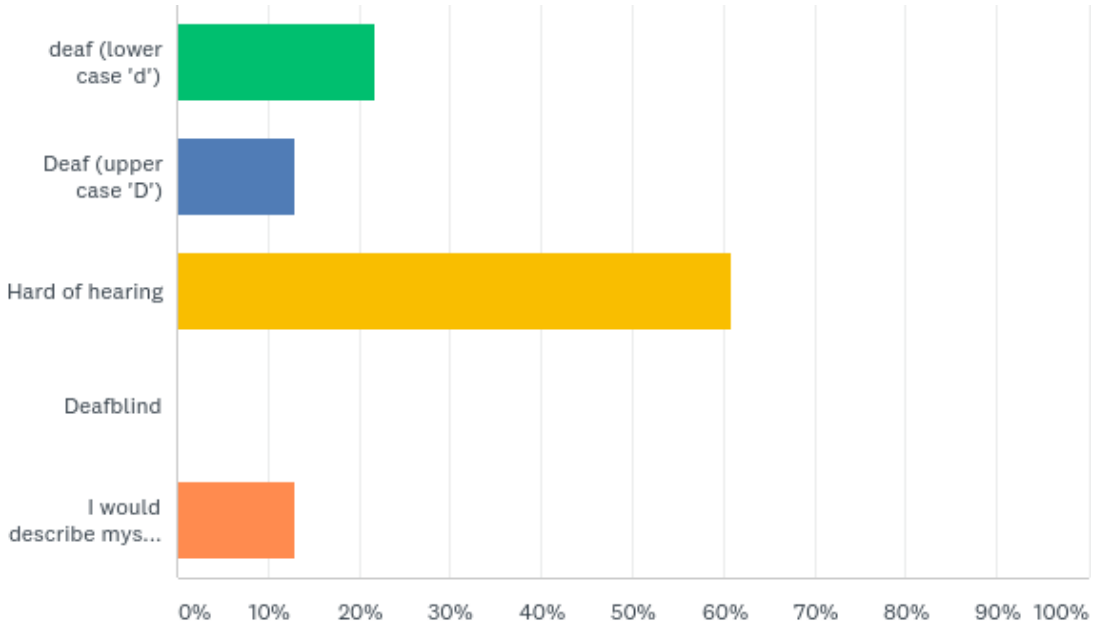
D/deaf or hard of hearing identity

In relation to Deafness or hearing loss, we asked "Which term or terms best describe how you think of yourself?" (23 answers)

The majority of respondents were hard of hearing (61%, 14), while 5 (22%) were deaf (with a lower case d) and 13% (3) identified as Deaf (with an upper case D).

3 said they would describe themselves in another way – only 2 of these gave responses and and said:

- *"a bit deaf"*
- *"Hearing impaired"*



ANSWER CHOICES	RESPONSES	
deaf (lower case 'd')	21.74%	5
Deaf (upper case 'D')	13.04%	3
Hard of hearing	60.87%	14
Deafblind	0.00%	0
I would describe myself in another way:	13.04%	3
Total Respondents: 23		

Communication

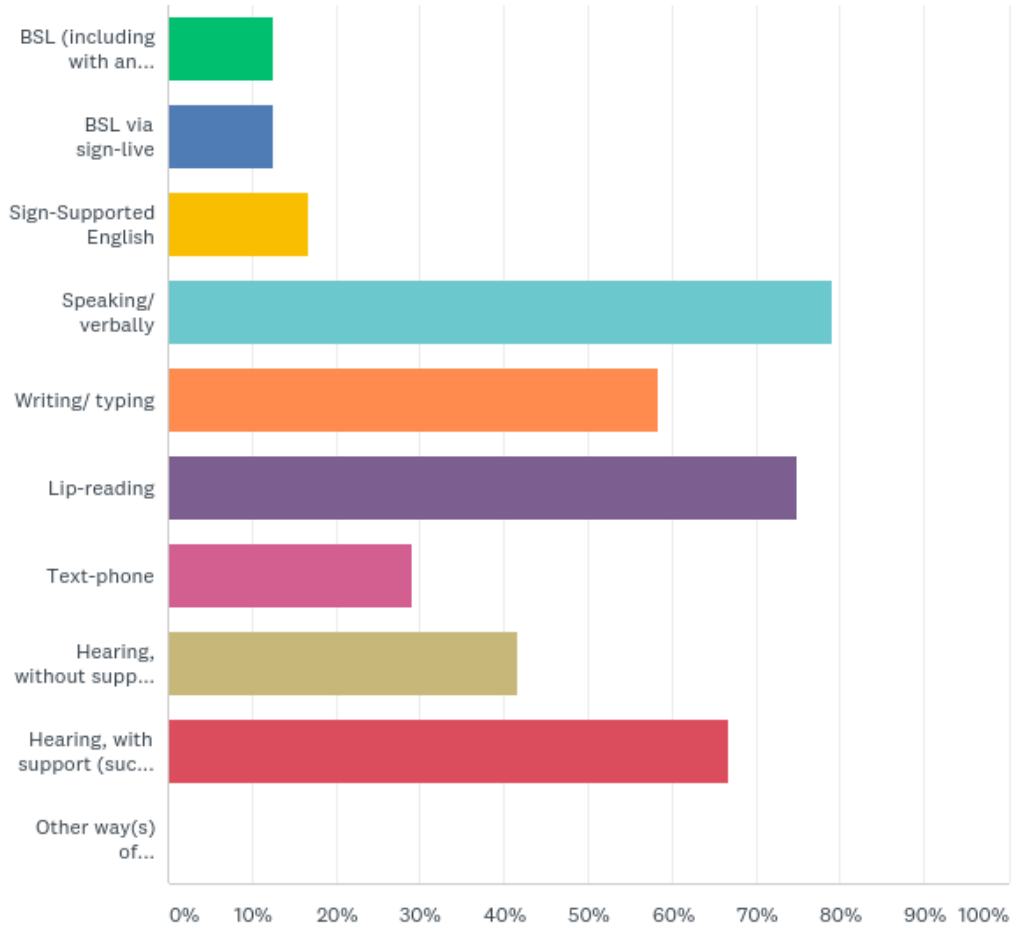
We asked respondents **"Which of the following ways do you communicate day-to-day?" (24 answers)**

We asked this question to gain an understanding of the styles of communication and support that respondents use, to inform any future development or recommendations around D/deaf/HoH inclusivity.

The 3 Deaf respondents confirmed they were also BSL users, and all 3 used Sign-Live (an online and remotely available BSL relay service). While this is a small sample, it indicates that sign-live is likely to already be widely used within the LGBTQ+ Deaf community.

79% (19) communicate verbally, and three quarters (75%, 18) use lip-reading. 58%, more than half (14) rely on writing/ typing to communicate day to day. 29% (7) use a text-phone, and 4 (17%) use sign-supported English.

42% (10) are able to use some hearing, without support, while 67% (16) utilise hearing with support (such as a hearing aid, cochlear implant, etc.)



Barriers: D/deaf and HoH

We asked respondents **"Have you experienced any of the following barriers to accessing healthcare as a D/deaf or heard of hearing person?" (21 answers)**

We offered the following options. Responses were distributed as follows:

ANSWER CHOICES	RESPONSES	
Having to make appointments in-person at the service location due to lack of online or text-relay options	23.81%	5
A lack of understand of D/deaf and HoH issues	61.90%	13
Barriers to communicating with reception staff	52.38%	11
Barriers to receiving test results	33.33%	7
Technical difficulties when using sign-live	4.76%	1
Inappropriateness of sign-live for sensitive appointments	0.00%	0
Mis-interpretation via sign-live or BSL interpreter	0.00%	0
Lack of access to sign-live for appointments	4.76%	1
Lack of access to an in-person BSL interpreter for appointments	9.52%	2
Lack of hearing loop available	28.57%	6
Lack of access to D/deaf and HoH inclusive resources and information	19.05%	4
Hearing staff discrimination because of being D/deaf or hard of hearing	42.86%	9
Healthcare professionals not being confident to discuss D/deaf and HoH issues	23.81%	5
Other aspects of identity not being taken into account in providing healthcare (such as sexual orientation, gender, disability, race, etc.)	42.86%	9
Other barrier(s) not listed:	14.29%	3
Total Respondents: 21		

The most prevalent issue was a lack of understand of D/deaf and HoH issues (62%, 13), followed by barriers to communicating with reception staff (11, 52%).

2 (5%) said lack of access to an in-person BSL interpreter for appointments was a barrier – however this represents 2 in 3 of BSL using respondents to the survey. A further one respondent each said that they had experienced technical difficulties using sign-live, or there was a lack of access to sign-live for appointments –which equates to 1 in 3 of BSL sign-live users surveyed. Reassuringly, no BSL or sign-live users reported that sign-live had not been appropriate for sensitive appointments or that mis-interpretation had taken place via an interpreter.

Nearly half (43%, 9) said that other aspects of their identity – such as sexual orientation, gender, disability or race for example – were not taken into account due to them being perceived first and foremost as a D/deaf or HoH person.

An equal number had unfortunately also experienced direct discrimination from hearing staff in response to their being D/deaf or HoH.

A third (7, 33%) faced issues receiving test results and 29% (6) had difficulties resulting from a lack of available hearing loop.

Nearly a quarter (24%, 5) said they had to make appointments in-person at the service location due to a lack of online or text-relay options.

Nearly 1 in 5 (19%, 4) experience healthcare professionals not being confident to discuss HoH and D/deaf issues.

It was notable that the reported Deaf-related inclusion barriers of the three Deaf respondents were distributed differently than their deaf and hard of hearing counterparts.

In particular, 100% (all three respondents) said a lack of understanding of Deaf issues and barriers to communicating with reception staff were the two main barriers.

Two in three said having to make appointments in-person was an issue and the same number said they experiences barriers to receiving test results.

Two in three also said hearing staff discrimination due to being Deaf was an issue they had experienced.

One in three said they had experienced technical difficulties using sign-live in appointments, and the same number said lack of access to a BSL interpreter, sign-live and hearing loop.

ANSWER CHOICES		RESPONSES	
Having to make appointments in-person at the service location due to lack of online or text-relay options		66.67%	2
A lack of understand of D/deaf and HoH issues		100.00%	3
Barriers to communicating with reception staff		100.00%	3
Barriers to receiving test results		66.67%	2
Technical difficulties when using sign-live		33.33%	1
Inappropriateness of sign-live for sensitive appointments		0.00%	0
Mis-interpretation via sign-live or BSL interpreter		0.00%	0
Lack of access to sign-live for appointments		33.33%	1
Lack of access to an in-person BSL interpreter for appointments		33.33%	1
Lack of hearing loop available		33.33%	1
Lack of access to D/deaf and HoH inclusive resources and information		0.00%	0
Hearing staff discrimination because of being D/deaf or hard of hearing		66.67%	2
Healthcare professionals not being confident to discuss D/deaf and HoH issues		0.00%	0
Other aspects of identity not being taken into account in providing healthcare (such as sexual orientation, gender, disability, race, etc.)		0.00%	0
Other barrier(s) not listed:	Responses	0.00%	0
Total Respondents: 3			

3 respondents gave other barriers:

- *"Doctors presuming that one is heterosexual."*
- *"Assuming 'normal' hearing and therefore not accommodating."*
- *"One stated that they found the question itself too long-winded"*

Further comments centred on the themes of:

- A lack of flexibility for D/deaf and HoH people, causing anxiety about missing appointments or opportunities to speak on the phone
  - *"They don't give you time to call & if you aren't in place where you can hear OK you run risk/ anxiety of missing your space if you don't answer. I've been in the awkward position where a GP calls back & I had to put on speaker phone & he started asking about if I had problems passing urine (which was a surprise to me as call wasn't about my urinary system)"*
  - *"Telephone communication is difficult and in person sometimes too much noise or the person not looking at you when speaking"*
- A lack of care and attention to ensuring a D/deaf or HoH person has heard or understood what has been said

    - *"Not taking the time to ensure you've heard not looking at you when speaking"*
- A general sense of disappointment with/ low opinion of GP surgery communication, and a sense that being D/deaf or HoH only adds to these difficulties
    - *"Gp surgery not good communicators at best of times let alone with multiple other difficulties"*
- A sense of not being seen as a whole person – different characteristics and experiences being separated
    - *"I am left with having to choose between discussing my gender, sexuality, pain, or my hearing issues. I can't discuss everything at once."*
- Frustration at needing to repeat oneself and remind healthcare providers at each appointment:
    - *"I am deaf from one ear, from birth and do not have a hearing aid or implant. […] Sometimes it can be frustrating to repeatedly remind that I am hard of hearing, perhaps because of a lack of visual cue."*

Barriers: LGBTQ+

We asked respondents **"Have you experienced any of the following barriers to accessing healthcare as an LGBTQ+ person?" (20 answers)**

The leading barrier experienced based on LGBTQ+ identity was heteronormativity, or the assumption that one is straight/ heterosexual, which was experience by a large majority of respondents (17, 85%).

100% of trans* respondents (nearly a third of overall respondents:, 30%, 6) said they were misgendered by staff.

This was followed by healthcare professionals not being LGBTQ-aware or inclusive, experienced by half of respondents (50%, 10). A further 45% (9) said healthcare professionals not being confident to discuss LGBTQ+ issues was a barrier.

40% (8) found a lack of LGBTQ resources to be an issue, and more than a third (35%, 7) experienced their partners not being recognised as such.

Nearly a third of respondents (30%, 6) said they were afraid to disclose their sexual orientation or gender identity due to fears of homo/ bi/ trans-phobia and the same number said they had actually experienced these forms of discrimination from staff in the past.

1 in 5 (20%, 4) experienced an assumption that they were cisgender.

ANSWER CHOICES	RESPONSES	
Healthcare professionals not being LGBTQ-aware and inclusive	50.00%	10
A lack of LGBTQ specific information and resources e.g. posters, leaflets	40.00%	8
Assumption that I'm cisgendered (i.e. people whose gender matches the gender they were assigned at birth)	20.00%	4
Assumption that I'm straight/heterosexual	85.00%	17
Being mis-gendered by staff (for example, the wrong name, pronoun and titles being used)	30.00%	6
Experiencing homo-/ bi- / transphobia from professionals	30.00%	6
LGBTQ partners not being recognised as such (e.g. referred to as 'friends')	35.00%	7
LGBTQ people being afraid to disclose their sexual orientation or gender identity because of fears about homo-/ bi- / transphobia	30.00%	6
Healthcare professionals not being confident to discuss LGBTQ issues	45.00%	9
Other barrier(s) not listed:	25.00%	5
Total Respondents: 20		

Barriers for the three Deaf respondents differed notably, and indicated much lower engagement with LGBTQ+ identity-based barriers than deaf and hard of hearing respondents.

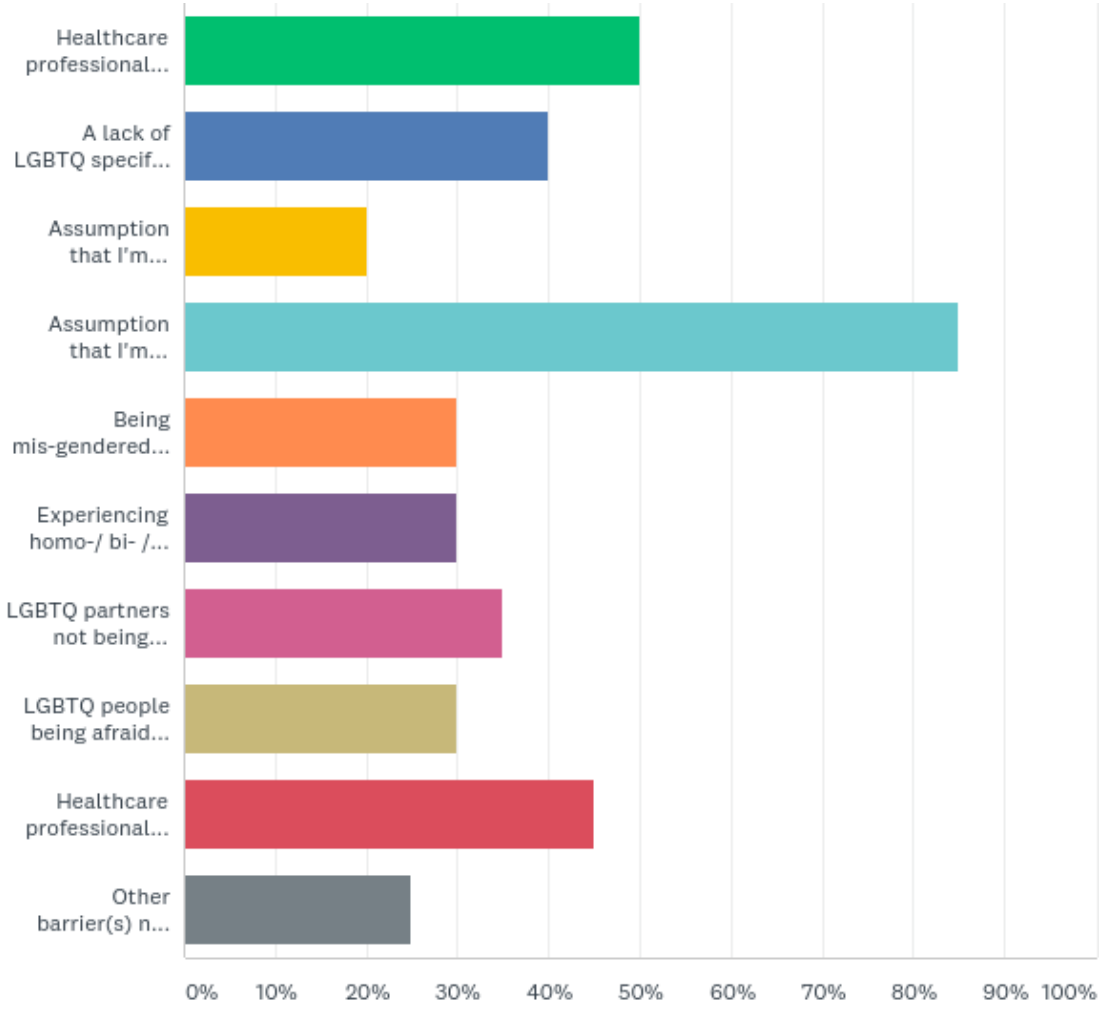
ANSWER CHOICES		RESPONSES	
Healthcare professionals not being LGBTQ-aware and inclusive		0.00%	0
A lack of LGBTQ specific information and resources e.g. posters, leaflets		0.00%	0
Assumption that I'm cisgendered (i.e. people whose gender matches the gender they were assigned at birth)		0.00%	0
Assumption that I'm straight/heterosexual		50.00%	1
Being mis-gendered by staff (for example, the wrong name, pronoun and titles being used)		0.00%	0
Experiencing homo-/ bi- / transphobia from professionals		0.00%	0
LGBTQ partners not being recognised as such (e.g. referred to as 'friends')		0.00%	0
LGBTQ people being afraid to disclose their sexual orientation or gender identity because of fears about homo-/ bi- / transphobia		0.00%	0
Healthcare professionals not being confident to discuss LGBTQ issues		0.00%	0
Other barrier(s) not listed:	Responses	50.00%	1
Total Respondents: 2			

Only two Deaf respondents completed the section, and one only gave the ‘assumption that I’m straight/heterosexual’ as a barrier. Another chose ‘other barrier not listed’ – their response is included below.

5 said other barrier not listed and stated:

- A sense that LGBTQ+ identity is taboo and not up for discussion
    - *“Im not surprise healthcare professionals aren't confident to discuss LGBTQ questions as the message I get is "Not for discussion" & this is really harmful”*
- Homophobia, stigma and assumptions related to HIV
    - Patient told the matron that they were using PREP and found her response to be “very homophobic”. When they attended for the operation, *the anaesthetist assumed they were HIV+. They also found the healthcare provider inflexible in exploring operation and recovery options, and did not take into account how the proposed interventions would have a negative effect on the patient’s sex life: “[the hospital] were also not receptive to the method of operation and recovery / ongoing potentially affecting anal intercourse and sexual intimacy.”*
- Assumptions based on race and skin colour were also an issue, and indicates the need for an intersectional approach to understanding D/deaf LGBTQ+ health inclusion
    - *“Assumptions on race and skin colour identity”*
- A lack of patience or flexibility was also described as a barrier, with hearing healthcare providers seeming impatient at needing to adapt to communicate with D/deaf and hard of hearing patients. This can result in patients having to wait to speak to someone who is more competent and able to respond to them. A Deaf survey respondent said:

- *“ often the hearing person was showing annoyed to try get information from me, if I turn up without interpreter as some appointments that do not need interpreter like having a blood test that was all often caught their expression was showing rude and can see the body language*



changed if I said can you repeat to speak slowly as I am deaf in a sec later appears into a panic or tell me to wait that is showing they do not know what to do with me! I am not a dog I am a person and waiting for confirming the appointment I turn up or ask for results or repeat prescription that is worse thing I had to deal with the reps at the clinic

- An example of cis-sexism was also given as a barrier, where a patient was persistently mis-gendered on the phone.
    - “Assumption by people I am in contact with on the telephone that I am gender male, even after I have explained fully that I am transgendered female and do not wish to be addressed as 'Sir' or prefixed 'Mr'. This was much improved after being allocated a new personal National Health number.”

Further comments clustered around the following theme:

- Heterosexist assumptions and inappropriate comments
    - "Every smear test I have ever had I always get asked if I am active sexually, I say yes and there is ALWAYS the assumption that I am heterosexual, because I am then asked if I could be pregnant or if I am using contraceptive, so I ALWAYS have to come out time and time again. I have also experienced inappropriate comments from a male doctor when I explained that I was a lesbian."
    - "*I am completely comfortable with my sexual orientation and don't mind having to come out, I just wish I didn't have to, as in that the assumption is always that you are heterosexual. I never make that assumption, so maybe there could be more training around that?"*

Intersecting Barriers: LGBTQ+ and D/deaf/HoH

We asked **"In your experience, do you find there are any specific barriers you face to accessing health care for being both LGBTQ+ and d/Deaf or hard of hearing?"** and provided a free text field.

Responses clustered around the following themes:

- The experience of being 'reduced' to one aspect of identity/ experience/ diagnosis and therefore not being seen and treated as a whole person. Individual issues being addressed at the expense of others, leaving patients feeling they need to choose one aspect of their experience to focus on, although they may actually be linked and intersecting.
    - *"I can't cover everything I would like to cover as I can't be queer, deaf/HoH, chronically ill, etc."*
    - *"There seems to be a lack of belief that I can be both and that problems are either one or the other"*
- Deafness being a more significant health inclusion barrier than sexual orientation, and frustration at needing
    - *"I don't notice about my sexual reference to them they do not ask me if I am a Gay or sexual choice! main mostly was focus on my deafness I have seen their barriers to me!!"*
- LGBTQ+ resources not being accessible for D/deaf/HoH people
    - *"Not all lbgtq resources are accessible for hard of hearing people"*
- LGBTQ+ and D/deaf/HoH issues experienced as separate and not related
    - *"The barriers I face are related to either my deafness or my LGBTQ+ identity, but not both"*
- Race and skin colour experienced as a more important barrier to health inclusion than either D/deaf/HoH or LGBTQ+ experience
    - *"I am more self-conscious/aware of my skin colour when accessing services"*

Several responses focused on one aspect of identity only, indicating that the question may not have been clear enough. These responses were incorporated into the specific section on those respective barriesr (i.e. either LGBTQ+ or D/deaf/HoH).

Negative healthcare experiences

We asked: **"If you have had one, can you please tell us about a negative healthcare experience when you felt excluded as a D/deaf/HoH and LGBTQ+ person? What made this a bad experience?"** and provided a free text field.

10 responses were given. It is notable that 8 f these related to D/deaf related barriers, and only 2 to LGBTQ+ issues, suggesting that D/deaf/HoH related barriers are a higher priority for most LGBTQ+ members of these communities.

- Heteronormativity and inappropriate comments in relation to sexual orientation – a preference for specific anatomy focused language, rather than language that suggests a certain type of sexual activity associated with a heterosexual orientation.
    - *"I recently had to have a polyp removed from my cervix and had to have a male doctor who once again asked all of the same questions about being sexually active, then when I said I was a lesbian made a really inappropriate comment probably because he didn't know what to say, but he could have simply said don't have penetrative sex for a week."*
    - *"Presumption my next of kin is my female friend not wife. Presumption my wife is a carer"*
- One respondent spoke of treatment at a private hospital as an NHS patient and stated they felt their treatment was particularly poor because they were an NHS patient, not private.
    - *"attitudes / homphphobia / lack of respect/ no dignity - even less when they find out you are NHS patient"*
- Lack of HoH communication awareness among reception staff
    - *"Receptionist at the GP surgery spoke with her hand over her mouth despite my wearing a hearing aid and asking her to speak a bit louder."*
- Difficulties booking appointments via phone – alternative methods needed
    - *"The thing I find worst is the lack of support regarding how to book an appointment. Most things are book on the phone."*
- Waiting room and reception communication issues – assuming hearing and relying on verbal cues for appointments, i.e. calling out names – meaning that D/deaf and hard of hearing patients miss being called to their appointments. This respondent also explained that they reported the incident to PAL but that it was never satisfactorily resolved.

  - *“once arrived clinic and Did wait, wait, wait, and wait then finally the person calling the name then walk off, I wasn't sure if it was me then again I feel embarrassed to ask if it is my name or not so best to wait for call my name again, nothing happened then did wait and long wait then realised I was the last person at the end of the room and no one was there! and I went to the rep, she said oh i forgot to tell the person that I am deaf, I was real pissed off at this point that why I wasn't called as I told them I am deaf, I had to scare the door for the person to come out and calling the names out I couldn't lipread that point due had to watch the door for too long, while others can listen to music or read papers I cannot then the rap siad oh it was too late as it is closed I blew my head said that is so bad for deaf people to able to access like this, this was sexual health clinic !!! i did not returned there ever again as I found another clinic in Worthing that wsa more helpful and I am still so annoyed due it is a long way for me to go there and back home, That was affected me as I am not impressed with health services to access to deaf people because they do not bother and taking for a grant to be hearing and use it daily that Deaf people couldn't have that chance due cannot hear a sound or words like me has to put up with watching people all the times as you know hearing people do have ears that never get tired but for us Deaf people rely on their and my eyes daily and all the times, we do get very tired eyes so often I missed the chance as didn't hear a word in to my ears so no information passing to me*
- Intersection of reception communication issues with trans exclusionary practices
  - *“When living full time for many years as a female prior to my gender reassignment operation. My prescriptions (including those for regular daily estrogen patches) were always made out in my male name. The Pharmacy assistant would call out that name when the prescription was ready. Because of my hearing loss, they often needed to repeat it loudly. It was embarrassing having to formally identify myself at the counter before being handed the medicines in front of others waiting in the pharmacy. There was no understanding that this was a sensitive matter.”*
- Medical jargon being used
  - *all was words everywhere I had to read and think again and again to taking the concept the words means mostly do use medical jargons all the times!!*
- Forcing suggestions of Cochlear implant
  - *once I had audiology appointment, during the consultation they asked me to suggest to have cochlear implant I clearly said no thanks then again asked me the same question and again I was bit annoyed that I made very clear that I do not need one and don't want one simple but the specialist kept on and on to make me have one I was*

uncomfortable about this matter and shout back no thanks! she was shocked and felt it is insulted me to force me to have this implant. I never went back to this clinic appointment and refused to return due of a bully at me, that was last year!!

- Being patronised and considered less intelligent due to having a visible disability
    - *"Not so much deaf Ness but certainly disability equating to me obviously having a lack of intellect"*
- Restrictions being placed on HoH patients without a formally 'deaf' diagnosis for using services that make communication more accessible – in this case the New Generation Text Service (NGT)
    - *"When hearing aids were not working I had to rely on NGT and was told by staff member that I was not deaf and should not be using NGT"*
- Lack of respect and timekeeping for BSL interpreted appointments
    - *"Resident doctor booking interpreter and then turning up 5 minutes prior to the end of the interpreter booking"*

Positive healthcare experiences

We asked: **"If you have had one, can you please tell us about a positive healthcare experience when you felt excluded as a D/deaf/HoH and LGBTQ+ person? What made this a bad experience?"** and provided a free text field. 10 responses were given:

4 in 10 positive experiences involved the patient's LGBTQ+ and D/deaf/HoH experiences both being acknowledged, respected and included.

- Inclusive of partners in a deaf-aware context
    - "*When I went to have my hearing aid fitted, the audiologist was inclusive, respectful and unsurprised by having my same sex partner with me."*
    - *"Asked if my wife wanted to attend appointments with me or access her own deaf awareness training"*
- Trans awareness, respect and inclusion alongside deaf awareness
    - *"A nurse who was deaf aware she made sure I understood what was happening, and dressed me in my wig and with my CI switched on in the post-operative ward before I recovered consciousness"*
    - *"Two years after the cancer op, I started living full time as a female. All the staff at the clinic were understanding and treated me with privacy and utmost dignity. After my gender reassignment operation […] the urology clinic staff again treated me with absolute respect and also took into account my worsening hearing by writing down anything that I hadn't heard correctly. I recently needed urethral surgery which was*

done at the same hospital with full respect and understanding of my hearing problems and with no mention of my former gender status. I felt safe and cared for by everyone in the department."

3 were experiences that were about being Deaf inclusive:

- Actively asking about hearing and communication needs
    - *"I was asked if I was HoH, it made the whole experience much safer and easier"*
- Linking up with resources and support
    - *"Mental health professionals generally very helpful. My care coordinator set up ngt on my phone when I was without hearing aids for six weeks"*
- Alternative booking options
    - *"When services allow for online booking is best."*

Other

- One Deaf respondent stated they hadn't had a positive experience and provided more information about a negative experience:
    - *"I do not attend locally any more due effect me with communication breakdown too many times in the past and I had no energy left to put it up again I have been living for over 50 years and had millions of barriers since the 1980's I always felt uncomfortable to attending the GP, Clinic, Hospital due of people look at me as a deaf and disabled and they talk about me I do not like I prefer respect and I do not look and making judgement to them they do, eg I went to rep for the ward for an appointment for eg audiology appointment the rap was shouting at me thanks !!!*
- One respondent gave general positive feedback about the Clause Nicole sexual health service
    - *"Claude Nicole - regular PREP testing , excellent , always first hand and amazing staff - why cannot the other parts of the NHS be the same ?* "
- One respondent didn't give specific positive feedback but indicated that sexual health and gynaecological appointments were particularly sensitive with regard to sexual orientation
    - *"I have had many positive experiences within the NHS, it only seems to be around gynaecological tests/procedures that my sexual orientation becomes relevant and/or assumed."*

What needs to change?

We asked: **"What do you think needs to change for LGBTQ+ D/deaf and HoH people to be better included in healthcare?"** and provided a free text field. 16 responses were given:

- Awareness training
  - *"greater awareness of being LGBTQ+ and sensitive to discussions"*
  - *"Just for people who are heterosexual not to assume that their patients are either heterosexual, cis gendered, etc. To just be a bit more aware and conscious of the kind of language they are using."*
  - *"Education and awareness training."*
  - *"understanding, training, simple awareness, very easy things"*
  - *"More information and education.*
  - *"For people to realise that hearing can be variable, dependent on hearing aids working"*
  - *"Much better deaf awareness and communication training Understanding trans issues around shyness, and comfort zones"*
- LGBTQ+ safer spaces
  - *"Safe space to discuss & not feel censored"*
  - *"I think just being able to say you aren't heterosexual without any fear of reprisal is a good start"*
- LGBTQ+ visibility – i.e. in resources
  - *"More visibility as I know Deaf LGBTQ+ people feel unheard, unseen and un-respected - probably due to ignorance and the ignorance of the intersectionality of multiple issues doesn't help."*
- Deaf accessible resources
  - *"Make resources friendly eg in spoken format."*
- Deaf information resources
  - *"Information about the wide spectrum of HoH/dDeaf conditions"*
- Better participation and representation
  - *"Involvement in patient groups."*
  - *"A double minority group, we need to be invited to patient participation groups"*
- Environmental adjustments and communication equipment for D/deaf/HoH patients
  - *"Background music makes H of H people unable to understand even close conversations."*
  - *"Loop System at receptions and clinic rooms"*
  - *"Hospitals have queues of patients sitting in waiting areas waiting at clinics, for blood tests, for X-rays, or for re-appointments and for discharging. All too often a name is called out for the next person on the treatment list. The name may be an inappropriate name or title for the pre-op and non-op transgender patients. Their assumed new names do not normally appear on hospital records and the staff often*

call out that name against a background of piped music or other continuous noise. It often needs repeating loudly until the patient can be alerted. \there is obvious embarrassment when responding, as a woman, to a call for 'Mr Jones', or as a man, to 'Miss Jones'."

Feedback on the survey

We asked respondents for their feedback on the survey itself, to learn about how we can improve accessibility for the D/deaf/HoH communities further in future engagement, and provided a free text field. Responses clustered around the following themes:

- Valuing in the opportunity to share about both LGBTQ+ and D/deaf/HoH experience
    - *"thank you for taking the time to ask us our experience. it's often the choice about being queer OR being HoH, but they are both part of who I am, and it's important that I'm treated as a whole person, rather than a set of 'minorities' good luck with this, much needed work"*
- General feedback
    - *"I found it good but very long."*
    - *"this survey is very useful , thank you for putting it together"*
    - *"assumption in this survey that I have a knowledge & time & interest in semantics of sexual identity politics."*
- Need for better BSL/ Deaf accessibility
    - *"this survey is not suitable for the Deaf Grassroot community and suggests you contact Surdi, they have the project called Sussex Deaf LGBT group."*
    - *"you should have BSL version translation on this survey due most of the Deaf LGBT are uncomfortable to use this survey and good luck"*

One-to-One Interviews

Interviews were offered and promoted alongside the online survey. It was promoted that they would be held at an accessible central Brighton venue, and travel expenses for participants were offered. It was also stated that they would be informal, confidential and lasted around 20-40 minutes. BSL interpretation was offered.

Through the online survey, five respondents expressed interest in an interview, either in person or remotely via email. Of these, only 1 interview was carried out in person. One responded via email and a further three were unable to participate due to lack of availability.

It is of interest that no community members expressed interest in an interview outside of the survey, and that very few who showed interest ultimately engaged. There may be learnings in this for promoting interviews alongside a more informal and easily accessible (for many) option, like an online survey. It may be that individuals wanted to choose ‘one or the other’ and opted for the less time-intensive option of the online survey.

Interviewee 1: “Jen”

“Jen” (name changed to protect anonymity) is a 20-something, hard of hearing and identifies as a woman and as lesbian. This interview was conducted via email.

Q: “What do you most wish healthcare providers understood about your experience as a hard of hearing and LGBTQ+ person?”

Jen indicated that she wished healthcare providers understood that being LGBTQ or hard of hearing are not ‘problems’, but the prejudicial attitudes that many cis-gender/heterosexual and hearing people hold towards them are. Whether or not these aspects of experience and identity are an issue depends on whether they are discriminated against. Having these two (or more) forms of discrimination

“It can be no big deal, or it can be a double discrimination.”

Q: “Are there other aspects of your experience or identity that affect your access to healthcare, or the quality of healthcare you receive?”

Jen said that noisy environments make interacting more difficult, and that brining someone along to appointments with her was an important help for making sure she doesn’t miss crucial information in medical appointments.

Jen also lives with mental health issues, and has found that this has been an additional source of stigma in healthcare settings. She has also experienced this stigma intersecting with stigma associated with her lesbian identity, with the experience of being told that her mental health issues are a result of her sexual orientation.

“I find it hard to hear in noisy environments, like wards. I need to bring someone with me to appointments to remember details, my memory isn't always spot on, and to hear extra details if it's noisy with background noise.

“I have mental health problems, and have been told in the past that it would be best if I didn't have a baby because I'm lucky to have the option of my wife having a baby, and straight couples don't have that luck. I've also been told that everything is as a result of being gay, and that it clearly caused my mental health problems. Which it hasn't in my case.”

Q: “Have healthcare providers ever signposted you to support groups or other resources (e.g. information leaflets, websites, support organisations) for deaf or LGBTQ+ communities? If so, what was your experience of these? If not, what would you have found helpful/relevant?”

Jen said she has never received any information about support or resources available for LGBTQ+ or deaf/ hard of hearing communities.

“No, I have had no information for LGBT+d.”

Q: “If you could change one thing to make it easier to access healthcare as a deaf LGBTQ+ person, what would it be? (Feel free to give more than one answer if you want!)”

Jen said that a positive change would be to make it clear that patients are welcome to bring someone along to their appointments to help with communication and make sure no important information is missed due to lack of hearing. She also suggested that some flexibility might be needed on the part of healthcare providers to make this possible.

“Encourage people to bring a friend/family member to appointments, rearrange them to accommodate if necessary, otherwise vital information is missed.”

Interviewee 2: “Kay”

“Kay” (name changed to protect anonymity) is an 80-something woman with a trans history who is experiencing age-related hearing loss.

The main issue Kay discussed was struggling to hear, and therefore be properly included healthcare settings. A key suggestion Kay made was that receptionists receive training in deaf awareness, to make simple adjustments like calling names out twice initially, to give hard of hearing people a chance to register their name.

“In an absolutely quiet atmosphere I’m alright – but the high frequencies are blotted out by background noise

“They announce it and they don’t always announce it clearly. I would love it if they understood this in GP Surgeries – if the receptionist repeated the name twice. Because you hear something and you think: ‘oh is that my name?’ And then you’re keyed up and if you hear the name a second time you’ll get it.

“If you do anything out of this, if this could be put across to GP and hospital receptionists – anywhere you need to wait to have your name called out. Particularly in hospitals the receptionist doesn’t always do the announcing. Someone might come to the door and call your name out, and if you’re reading a magazine or not looking up, you’re likely to miss it.

“It’s such a simple little thing that would really help.”

Kay gave a ‘best practice’ example of a surgery she had attended that had been particularly inclusive of her as a hard of hearing person. This included clear announcements from reception and a screen on which patients can see their name given.

“There’s a nice clear announcement and then a board where people waiting can look up and see if it’s their name. They also have enough receptionists around who can tell you not only what to do, but how long you’re likely to wait.”

I asked Kay about her experience as an LGBTQ hard of hearing person and how these interact for her. She explained that she doesn’t identify as trans, but rather as having a trans history.

“I don’t identify myself as a trans person. I don’t say ‘I’m trans, look after me’. I’m a woman doing a job for older people. It never comes up [in my job]. I have passed through a phase where perhaps I needed the support and comradeship of other people like me, but now I regard myself as a woman doing whatever any other woman would do.”

Kay described her confident personality as a protective factor in her experience as a hard of hearing person with a trans history, and recognised that shy or less confident trans deaf individuals may struggle more with engaging the challenges within healthcare settings.

“If I was shy about my persona as well, that would make things much worse. I’m one of those bold people that meets any challenge that comes along, but not everyone is like that.”

Key Findings

Staff confidence and awareness: LGBTQ+ and D/deaf/HoH

Staff confidence presented as an issue concerning discussing both LGBTQ+ and D/deaf/HoH issues. However, it is interesting to note that respondents encountered a lower rate of the issue of healthcare professionals not being confident to discuss issues related to their D/deaf or HoH experience (19%, 4 respondents), as compared with their LGBTQ+ identity (45%, 9 respondents). This indicates a lower perceived general level of confidence discussing LGBTQ+ issues than D/deaf/HoH in staff.

This was reflected in comments through a sense that LGBTQ+ identity in particular is taboo:

“I’m not surprised healthcare professionals aren't confident to discuss LGBTQ questions as the message I get is "Not for discussion" and this is really harmful”

‘Confidence’, as used here, is distinct from ‘awareness’ or ‘understanding’ which showed a the opposite outcome for D/deaf/HoH as compared with LGBTQ+ individuals.

Indeed, a highly prevalent issue was a lack of understanding of D/deaf and HoH issues (62%, 13) and healthcare professionals not being LGBTQ-aware or inclusive, experienced by half of respondents (50%, 10).

In response to this, a call for awareness training – for both LGBTQ+ and D/deaf/HoH awareness – was strong throughout the survey, with several individual comments in response to the ‘what needs to change?’ question making specific reference to this.

LGBTQ+ Stigma and Discrimination

Nearly a third of respondents (30%, 6) said they were afraid to disclose their sexual orientation or gender identity due to fears of homo/ bi/ trans-phobia and the same number said they had actually experienced these forms of discrimination from staff in the past.

Several respondents reported a general sense of poor attitudes regarding LGBTQ+ identity, stigma, homophobia -- *“attitudes / homphphobia / lack of respect/ no dignity”*

One respondent gave an example of experiencing stigma and assumptions related to their HIV status, whereby they informed the matron that they were using PREP

and found her response to be “very homophobic”. When they attended for the operation, the anaesthetist assumed they were HIV+.

An interviewee spoke about stigma related to her mental health as well as their LGBTQ identity being pathologised by healthcare professionals:

“I have mental health problems, and have been told in the past that it would be best if I didn't have a baby because I'm lucky to have the option of my wife having a baby, and straight couples don't have that luck. I've also been told that everything is as a result of being gay, and that it clearly caused my mental health problems”

D/deaf and hard-of-hearing Stigma and Discrimination

Nearly half (43%, 9) had experienced direct discrimination from hearing staff in response to being D/deaf or HoH.

One respondent highlighted their frustrations with being treated as less than competent or intelligent by hearing staff due to being Deaf, reflecting research in the field that – because many deaf community members have not mastered spoken language they are perceived as having a communication disorder, rather than a legitimate communication difference (Leigh 2009).

Reflecting an experience of being subject to ableism related to a disability (not connected to deafness) another respondent to the survey said a barrier to interacting with healthcare staff was *“not so much deafness but certainly disability equating to me obviously having a lack of intellect”*

Awareness raising training is required to address staff mis-perceptions and stereotyping of both D/deaf/HoH individuals and those with disabilities.

One Deaf respondent shared an incident in which the suggestion they have a cochlear implant was forced even when they had declined:

“O*nce I had audiology appointment, during the consultation they asked me to suggest to have cochlear implant I clearly said no thanks then again asked me the same question and again I was bit annoyed that I made very clear that I do not need one and don't want one simple but the specialist kept on and on to make me have one I was uncomfortable about this matter and shout back no thanks! she was shocked and felt it is insulted me to force me to have this implant. I never went back to this clinic appointment and refused to return due of a bully at me, that was last year!”*

One Deaf respondent expressed their frustration and disappointment with the healthcare they have received for many years. They say they feel reduced to being 'deaf' and 'disabled' by staff and are not treated with respect:

"I do not attend locally any more due effect me with communication breakdown too many times in the past and I had no energy left to put it up again I have been living for over 50 years and had millions of barriers since the 1980's I always felt uncomfortable to attending the GP, Clinic, Hospital due of people look at me as a deaf and disabled and they talk about me I do not like I prefer respect and I do not look and making judgement to them they do, eg I went to rep for the ward for an appointment for eg audiology appointment the rap was shouting at me thanks !!!"

Heteronormativity

The more prevalent barrier to accessing healthcare experienced based on LGBTQ+ identity was heteronormativity, the assumption that one is straight/ heterosexual, which was experience by a large majority of respondents (85%).

This was a theme repeated throughout the comments on the online survey.

"*I am completely comfortable with my sexual orientation and don't mind having to come out, I just wish I didn't have to, as in that the assumption is always that you are heterosexual. I never make that assumption, so maybe there could be more training around that?"*

Inappropriateness of comments from healthcare staff on learning that a patient is LGBTQ+ was also reported, along with a preference for specific anatomy-focused language with regard to sex, rather than language that assumes and implies penetrative heterosexual sex as the norm.

"I recently had to have a polyp removed from my cervix and had to have a male doctor who once again asked all of the same questions about being sexually active, then when I said I was a lesbian made a really inappropriate comment probably because he didn't know what to say, but he could have simply said don't have penetrative sex for a week."

Connected with heteronormativity, more than a third of respondents (35%) had experienced their partners not being recognised as such.

"Presumption my next of kin is my female friend not wife. Presumption my wife is a carer"

Deconstructing heteronormativity and increasing levels of confidence and comfort around discussing LGBTQ+ issues were given as important positive steps that could be taken towards a greater sense of safety to access healthcare:

When we asked what would help improve the situation, two respondents commented:

“Safe space to discuss & not feel censored”

“I think just being able to say you aren't heterosexual without any fear of reprisal is a good start”

“Just for people who are heterosexual not to assume that their patients are either heterosexual, cis gendered, etc. To just be a bit more aware and conscious of the kind of language they are using.”

Cisnormativity and mis-gendering

Assumptions that a person is cisgender (cisnormativity) and mis-gendering (addressing a person with an incorrect name, pronoun, title or other gender indicator) were given throughout the survey as barriers to accessing services from trans* communities.

100% of trans* respondents (nearly a third of overall respondents at 30%) said they had experienced being mis-gendered by staff. 1 in 5 overall respondents (20%, 4) experienced an assumption that they were cisgender.

An example of cis-normativity was given, where a patient was persistently mis-gendered on the phone.

“Assumption by people I am in contact with on the telephone that I am gender male, even after I have explained fully that I am transgendered female and do not wish to be addressed as 'Sir' or prefixed 'Mr'. This was much improved after being allocated a new personal National Health number.”

Hearing-centric assumptions

Survey respondents also commented on the fact that, without obvious markers unless a person is wearing an assistive device such as a hearing aid, deafness or hearing loss is often invisible and hearing is unhelpfully assumed. Much like individuals frustration at being required to repeatedly ‘come out’ as LGBTQ+, needing to repeatedly inform or remind healthcare staff of D/deafness or hearing loss was a frustrating barrier for some.

For example *“Assuming 'normal' hearing and therefore not accommodating”* was given by one respondent as an example of a barrier, while another explained: *“I am deaf from one ear, from birth and do not have a hearing aid or implant. […]*

Sometimes it can be frustrating to repeatedly remind that I am hard of hearing, perhaps because of a lack of visual cue."

Concurrently, actively being asked about hearing and communication needs was provided by one respondent as an example of a helpful positive step towards better health inclusion:

"I was asked if I was HoH, it made the whole experience much safer and easier"

Recognising intersectionality

The survey also revealed an experience of a tendency of some healthcare staff to reduce patients to one marginalised characteristic only, and ignore other aspects of identity and experience at the expense of this, reducing the individual to one aspect of themselves only.

This reflects what Leigh (2012) has called "the fallacy of homogeneity", highlighting instead "the reality of intersections" or 'intersectionality' (p. 61). Leigh writes:

"The use of the words 'deaf' or 'Deaf' to describe a person are inadequate for the purpose of defining who that person is. The D/deaf community is a composite of the same racial, ethnic, religious, sexual orientation, and other differences that exist in society at large. To be aware of this is to be that much more competent in providing appropriate [services]." (p. 61)

Nearly half (43%, 9) said that other aspects of their identity – such as sexual orientation, gender, disability or race for example – were not taken into account due to them being perceived first and foremost as a D/deaf or HoH person.

This was also reflected throughout comments, where a sense of not being seen as a whole person was expressed:

"I am left with having to choose between discussing my gender, sexuality, pain, or my hearing issues. I can't discuss everything at once."

This tendency to reduce individuals to one aspect of identity, experience or diagnosis prevents an understanding of the ways in which these factors will inevitably inter-relate and intersect. This lack of nuance in understanding can be frustrating for patients, and result in their concerns not being adequately addressed or treated:

"I can't cover everything I would like to cover as I can't be queer, deaf/HoH, chronically ill, etc."

"There seems to be a lack of belief that I can be both and that problems are either one or the other"

Reflecting this, 4 in 10 reported positive healthcare experiences involved the patient's LGBTQ+ and D/deaf/HoH experiences both being acknowledged, respected and included. For example, respondents talked about how they appreciated having their partners recognised as such within a deaf-aware context:

"*When I went to have my hearing aid fitted, the audiologist was inclusive, respectful and unsurprised by having my same sex partner with me."*

"Asked if my wife wanted to attend appointments with me or access her own deaf awareness training"

Trans awareness, respect and inclusion alongside deaf awareness was similarly given as an example of a positive experience:

"A nurse who was deaf aware she made sure I understood what was happening, and dressed me in my wig and with my CI switched on in the post operative ward before I recovered consciousness"

"All the staff at the clinic were understanding and treated me with privacy and utmost dignity. After my gender reassignment operation […] the [clinic staff] again treated me with absolute respect and also took into account my worsening hearing by writing down anything that I hadn't heard correctly. I recently needed [surgery] which was done at the same hospital with full respect and understanding of my hearing problems and with no mention of my former gender status. I felt safe and cared for by everyone in the department."

One respondent commented on appreciating the opportunity to complete the survey because it provided any opportunity to voice and have recognised the intersection of their HoH experience and LGBTQ+ identity:

"Thank you for taking the time to ask us our experience. it's often the choice about being queer OR being HoH, but they are both part of who I am, and it's important that I'm treated as a whole person, rather than a set of 'minorities' good luck with this, much needed work"

Intersecting marginalisations

LGBTQ+ and D/deaf/HoH

Related to the above, several respondents shared experiences and views regarding the intersection of their D/deaf/HoH and LGBTQ+ identities and experiences, and how these impacted on their ability to access healthcare.

"[Being LGBTQ and deaf] can be no big deal, or it can be a double discrimination."

For example, one respondent described a time that communication issues with reception, related to a lack of deaf-awareness, intersected with their being mis-gendered due to medical records holding incorrect information.[6]

"W*hen living full time for many years as a female prior to my gender reassignment operation my prescriptions (including those for regular daily estrogen patches) were always made out in my male name. The Pharmacy assistant would call out that name when the prescription was ready. Because of my hearing loss, they often needed to repeat it loudly. It was embarrassing having to formally identify myself at the counter before being handed the medicines in front of others waiting in the pharmacy. There was no understanding that this was a sensitive matter."*

"All too often a name is called out for the next person on the treatment list. The name may be an inappropriate name or title for the pre-op and non-op transgender patients. Their assumed new names do not normally appear on hospital records and the staff often call out that name against a background of piped music or other continuous noise. It often needs repeating loudly until the patient can be alerted. There is obvious embarrassment when responding, as a woman, to a call for 'Mr Jones', or as a man, to 'Miss Jones'."

These findings reflect the view of scholar on Deaf and multiple minority characteristic intersectionality, Leigh (2012), who writes:

"On the basis of their sexual orientation, lesbian, gay, bisexual and transgendered (sic.) (LGBT) people face unique and stressful challenges as they interact with societies that continue to view heterosexuality as the only permissible norm. […] Add deaf people to this mix and you have the makings of a multiple minority status issues that they have to confront depending upon the extent to which their D/deafness, their sexual orientation, and/or their ethnic identity are salient." (p. 69)

Disability

It is of note that a high proportion of respondents, nearly 1 in 3 (30%, 6 each) also live with a mental health difficulty and/or a physical impairment of mobility issue, while 1 in 5 (4, 20%) live with a long-term illness. This indicates that this intersection

[6] A previous HIP report into Monitoring Gender, Sexual Orientation and Trans Status (2018) highlighted the existing issues with properly recording and monitoring correct patient pronouns, titles, names and other gender indicators https://www.switchboard.org.uk/wp-content/uploads/2018/04/LGBT-HIP-Monitoring-Report-April-2018.pdf

of identity may experience a significantly higher prevalence of certain forms of disability, and therefore both require greater interaction with the healthcare system, just as they simultaneously experience greater barriers to inclusion within it.

Further research into the intersection of LGBTQ+ and D/deaf/HoH experiences with regard to health inequalities is required to better understand and address this.

Race and skin colour

"Assumptions on race and skin colour identity" were also provided by one respondent as an issue, further highlighting the need for an intersectional approach to understanding D/deaf LGBTQ+ health inclusion. This respondent went on to explain that they experience responses to their their race and skin colour as a more important barrier to health inclusion than either D/deaf/HoH or LGBTQ+ experience: *I am more self-conscious/aware of my skin colour when accessing services"*

It is of note that only 15% (3) of survey respondents were people of colour, and therefore that views regarding the intersection of race, skin colour, ethnicity and LGBTQ+ and D/deaf/HoH experiences are under-represented here. Again, further research and engagement may be necessary to develop a thorough understanding of this intersection and its implications for health access.

Indeed, Leigh (2012), writes:

"It has long been thought that for diverse deaf people (sic.), being deaf trumps all differences and brings them together. However, deaf people are not immune to the effects of their larger societies and to the pervasive influence of White skin privilege. Racism and exclusion from the dominant society is a real experience for many deaf individuals of ethnic minority status." (p. 64)

Highlighting the "strain and versatility" required by Deaf BAME individuals to participate in each respective mainstream culture, a UK study by Ahmas, Atkin and Jones (2002) looked at how 56 Pakistani-Muslim Deaf individuals related with their multiple minority identities. The study "found that the majority indicated a preference for a Deaf identity to build up a stronger sense of self against an isolating, unfriendly, and inaccessible hearing environment. However, this implied endorsement of a White, Christian-based Deaf identity due to the lack of a Pakistani Muslim-based Deaf group to identify with, even though the participants recognised the need to endorse their ethnic Pakistani identity. This inherently creates an ambivalent, strained relationship with the Deaf community. The importance of situation demands fluidity in terms of which aspect of the self to endorse, as when participants are participating in Muslim religious events or mingling with White Deaf counterparts." (Leigh 2002, p. 65)

Deaf inclusion and under-representation

It is notable that responses from the LGBTQ+ Deaf (upper case 'D') community were limited to three, and therefore under-represented in the engagement. This is likely to reflect issues with Deaf inclusion in the wider LGBTQ+ community in general. Furthermore, the limited inclusivity of the survey due to a lack of BSL clips was highlighted through some comments, and through engagement with DeafCOG.

One Deaf respondent gave the feedback: *"this survey is not suitable for the Deaf Grassroot community"* and another suggested *"you should have BSL version translation on this survey due most of the Deaf LGBT are uncomfortable to use this survey."*

While 1-1 interviews with BSL interpretation were offered and promoted, no Deaf LGBTQ+ individuals chose this option, highlighting the need for further work around Deaf inclusion and engagement in the LGBTQ+ voluntary sector, particularly with regard to Switchboard's traditional online survey-based engagement methods.

Communication Barriers

Barriers to communicating with reception staff was an issue for more than half of respondents (11, 52%). In addition to this 29% (6) had experienced difficulties resulting from a lack of available hearing loop, a third (7, 33%) faced issues receiving test results and nearly a quarter (24%, 5) said they had to make appointments in-person at the service location due to a lack of online or text-relay options.

Significant time was given by respondents to explaining the hearing-related communication barriers they experiences when trying to access healthcare, and more responses (in terms of wordcount) were given on this topic than on any other issue in the survey.

An example of this included a lack of communication flexibility for D/deaf and HoH people, causing anxiety about missing appointments or opportunities to speak on the phone:

"They don't give you time to call & if you aren't in place where you can hear OK you run risk/ anxiety of missing your space if you don't answer. I've been in the awkward position where a GP calls back & I had to put on speaker phone & he started asking about if I had problems passing urine (which was a surprise to me as call wasn't about my urinary system)"

"Telephone communication is difficult and in person sometimes too much noise or the person not looking at you when speaking"

A lack of care and attention to ensuring a D/deaf or HoH person has heard or understood what has been said was also reported:

“Not taking the time to ensure you’ve heard not looking at you when speaking”

A general sense of disappointment with/ low opinion of GP surgery communication was expressed, and a sense that being D/deaf or HoH only adds to these difficulties

“Gp surgery not good communicators at best of times let alone with multiple other difficulties”

A lack of patience or flexibility was also described as a barrier, with hearing healthcare providers seeming impatient at needing to adapt to communicate with D/deaf and hard of hearing patients. This can result in patients having to wait to speak to someone who is more able to respond to them. A Deaf survey respondent said:

“Often the hearing person was showing annoyed to try get information from me, if I turn up without interpreter as some appointments that do not need interpreter like having a blood test that was all often caught their expression was showing rude and can see the body language changed if I said can you repeat to speak slowly as I am deaf in a sec later appears into a panic or tell me to wait that is showing they do not know what to do with me! I am not a dog I am a person and waiting for confirming the appointment I turn up or ask for results or repeat prescription that is worse thing I had to deal with the reps at the clinic

Difficulties booking appointments via phone and the need for alternative methods was also shared:

“The thing I find worst is the lack of support regarding how to book an appointment. Most things are book on the phone.”

“When services allow for online booking is best.”

Waiting room and reception communication issues – assuming hearing and relying on verbal cues for appointments, i.e. calling out names – were also a significant issue, meaning that D/deaf and hard of hearing patients miss being called to their appointments.

One Deaf respondent related a frustrating experience of waiting to be invited in for an appointment, and missing their name being called due to reception staff failing to communicate effectively:

“once arrived clinic and Did wait, wait, wait, and wait then finally the person calling the name then walk off, I wasn't sure if it was me then again I feel embarrassed to ask if it is my name or not so best to wait for call my name again, nothing happened then did wait and long wait then realised I was the last person at the end of the room

and no one was there! and I went to the rep, she said oh i forgot to tell the person that I am deaf, I was real pissed off at this point that why I wasn't called as I told them I am deaf, I had to scare the door for the person to come out and calling the names out I couldn't lipread that point due had to watch the door for too long, while others can listen to music or read papers I cannot then the rap siad oh it was too late as it is closed I blew my head said that is so bad for deaf people to able to access like this, this was sexual health clinic !!! i did not returned there ever again as I found another clinic in Worthing that wsa more helpful and I am still so annoyed due it is a long way for me to go there and back home, That was affected me as I am not impressed with health services to access to deaf people because they do not bother and taking for a grant to be hearing and use it daily that Deaf people couldn't have that chance due cannot hear a sound or words like me has to put up with watching people all the times as you know hearing people do have ears that never get tired but for us Deaf people rely on their and my eyes daily and all the times, we do get very tired eyes so often I missed the chance as didn't hear a word in to my ears so no information passing to me"

Further to this, an interviewee explained:

"They announce it and they don't always announce it clearly. I would love it if they understood this in GP Surgeries – if the receptionist repeated the name twice. Because you hear something and you think: 'oh is that my name?' And then you're keyed up and if you hear the name a second time you'll get it […] "It's such a simple little thing that would really help."

One respondent also highlighted that having someone along to support them in their appointment helped a great deal with addressing communication issues, and making sure they had all the key information. Letting patients know they are welcome to bring a supportive person to appointments was suggested as a means of addressing this:

"I find it hard to hear in noisy environments, like wards. I need to bring someone with me to appointments to remember details, my memory isn't always spot on, and to hear extra details if it's noisy with background noise.

"Encourage people to bring a friend/family member to appointments, rearrange them to accommodate if necessary, otherwise vital information is missed."

Environmental barriers

Environmental barriers to communication for D/deaf/HoH patients were also an issue, yet could be simply addressed:

"Background music makes H of H people unable to understand even close conversations."

Several respondents commented that simple environmental adjustments, such as eschewing background music, ensuring hearing loops are fitted and making visual screens of information available would greatly improve their access.

BSL Interpretation Access

2 in 3 BSL using Deaf respondents to the survey (5%) said lack of access to an in-person BSL interpreter for appointments was a barrier, while a further one respondent each said that they had experienced technical difficulties using sign-live, or there was a lack of access to sign-live for appointments –which equates to 1 in 3 of BSL sign-live users surveyed. Reassuringly, no BSL or sign-live users reported that sign-live had not been appropriate for sensitive appointments or that mis-interpretation had taken place via an interpreter.

The 3 Deaf-identified respondents confirmed they were also BSL users, and all 3 used Sign-Live (an online and remotely available BSL relay service). While this is a small sample, it indicates that sign-live is likely to already be widely used within the LGBTQ+ Deaf community.

For one of these individuals, a lack of timekeeping for BSL interpreted appointments was reported:

“Resident doctor booking interpreter and then turning up 5 minutes prior to the end of the interpreter booking”

Unfortunately, no Deaf LGBTQ+ individuals volunteered for interview. However, it would be helpful to understand about any specific BSL interpretation needs or experiences that may be specific to LGBTQ+ communities and individuals.

Inclusive resources

40% (8) found a lack of LGBTQ resources to be an issue, and several respondents commented on issues of resources not being D/deaf/HoH includive, with medical jargon providing a particular barrier for BSL using Deaf individuals, in particular@

“Not all lbgtq resources are accessible for hard of hearing people”

“*all was words everywhere I had to read and think again and again to taking the concept the words means mostly do use medical jargons all the times!!”*

It was suggested that resources are made accessible, in a range of formats, and that information is provided *“about the wide spectrum of HoH/dDeaf conditions”.*

LGBTQ+ visibility was also requested in D/deaf/HoH resources:

“More visibility as I know Deaf LGBTQ+ people feel unheard, unseen and un-respected - probably due to ignorance and the ignorance of the intersectionality of multiple issues doesn't help.”

Priorities between D/deaf/HoH and LGBTQ+ related barriers

A theme throughout the survey statistics and comments reflected the experience that healthcare barriers related to D/deaf/HoH experience are greater – in terms of prevalence – for many than are LGBTQ+ specific issues.

For instance, it is notable that 8 of the 10 ‘negative healthcare experiences’ provided related to D/deaf related barriers, and only 2 to LGBTQ+ issues, suggesting that D/deaf/HoH related barriers may be a higher priority for most LGBTQ+ members of these communities.

Again, we must hesitate here to ‘separate’ these aspects of identity, which of course intersect. However, it is notable that respondents reported lower levels of awareness and understanding, and higher levels of stigma, associated with being D/deaf/HoH as compared with being LGBTQ+, despite perceived staff ‘confidence’ being lower for the latter.

Distinctions in Culturally Deaf LGBTQ+ Experiences

This distinction between the importance of LGBTQ+ and Deaf-related barriers was even more apparent for Deaf (i.e. culturally Deaf BSL users), with reported barriers for the three Deaf respondents differing notably from those of deaf and HoH respondents.

A key theme here was an indication of much lower engagement with LGBTQ+ identity-based barriers than deaf and hard of hearing respondents. Only two Deaf respondents completed the section about LGBTQ+-related barriers, and one only gave the ‘assumption that I’m straight/heterosexual’ as a barrier. Another only chose ‘other barrier not listed’. This was distinct from deaf and HoH respondents, who tended to choose several different barriers for each section.

One Deaf respondent said

"*I don't notice about my sexual preference to them they do not ask me if I am a Gay or sexual choice! main mostly was focus on my deafness I have seen their barriers to me!!"*

It was also notable that the reported Deaf-related inclusion barriers of the three Deaf respondents were distributed differently than their deaf and hard of hearing counterparts.

In particular, 100% (all three respondents) said a lack of understanding of Deaf issues and barriers to communicating with reception staff were the two main barriers.

This is in contrast to the statistics for hard of hearing and deaf respondents, for whom a lack of understand of D/deaf and HoH issues was given at 62%, followed by barriers to communicating with reception staff, at 52%.

Two in three said having to make appointments in-person was an issue and the same number said they experiences barriers to receiving test results. Two in three also said hearing staff discrimination due to being Deaf was an issue they had experienced. One in three said they had experienced technical difficulties using sign-live in appointments, and the same number said lack of access to a BSL interpreter, sign-live and hearing loop.

Deaf and LGBTQ+ community divisions

The noted tendency for Deaf survey respondents to highlight their Deaf identity over their LGBTQ+ identity may also speak to the difficulties in integration of hearing and Deaf LGBTQ+ communities.

Leigh (2012) highlights the existence of ambivalence, strain and the need for versatility for Deaf LGBTQ+ individuals in the respective 'mainstream' of each community – as a Deaf person in hearing-dominated LGBTQ+ community, and an LGBTQ+ person in a cis-heterosexual-dominated Deaf community.

This strain is reflected in the history of LGBTQ+ Deaf inclusion in Brighton and Hove. While, according to Poplett (date unknown), local Deaf LGBT people are now involved in the Deaf community in Brighton & Sussex, there is a more troubled history of inclusion in the area. For instance, "Brighton Deaf Club 'banned' Deaf lesbians and gays in 2000", and "some Deaf members petitioned for Deaf lesbians and gays to be banned after one Deaf Club event were peopled by Deaf lesbians and gays during the 2000 Pride weekend."

“Only after the Equal Opportunities Policy was adopted several years later, the Deaf Club was open to Deaf LGBT people.” However, he notes that “Deaf LGBT people still refuse to come as the old attitudes remain.”

Likewise, many mainstream hearing-oriented LGBTQ+ spaces and events are not accessible or welcoming spaces for Deaf individuals, with a lack of BSL interpretation or encountering stigma and discrimination being potential issues.

Participation and representation

Comments and statistics throughout the survey support the need for greater participation and representation of D/deaf/HoH LGBTQ+ communities in healthcare provision, and several comments directly supported this. For example, when asked ‘What needs to change?’ two respondents stated:

“Involvement in patient groups.”

“A double minority group, we need to be invited to patient participation groups”

Conclusions

It was interesting but unfortunate to note a synergy with previous HIP reports regarding the precedence of heteronormativity and cisnormativity as key barriers for LGBTQ+ communities accessing healthcare, indicating a need for greater training around these issues, as well as a cultural shift in organisational attitudes and unconscious bias vis a vis LGBTQ+ identity. This was particularly expressed through mis-identification of partners as friends or family members, and through sexual and gynaecological health questions that assumed a cis-heteronormative idea of 'sex' as penetrative sex between a cis-man and a cis-woman, leaving LGBTQ+ individuals to repeatedly 'come out' and feel the need to explain, justify or describe their sexual practices to healthcare staff.

In addition to this, assumptions about levels of hearing created an intersecting layer of difficulty in healthcare interactions, whereby communication needs and preferences were not openly discussed or asked about by staff, resulting in patients missing important information and raising levels of anxiety.

Indeed, it was also apparent through the survey and interviews that both LGBTQ+ and D/deaf/HoH identity each contributed to raised levels of anxiety communicating and engaging within a healthcare context, and that some unique intersections exist. Through this particular engagement, experiences of trans individuals in particular highlighted the intersecting difficulties relating to communication and being mis-gendered that resulted in upsetting, embarrassing and frustrating situations.

Positive situations and hoped-for improvements tended to centre around feeling invited, welcome and safe to discuss intersecting aspects of their experience and identity as relevant to their healthcare, and to not be 'reduced' to one characteristic. Indeed, as Leigh (2012) writes, "The pull for identity synthesis rather than splitting off parts of oneself can be compelling. This is facilitated by the presence of accepting communities where such individuals can find a safe haven" (p. 69).

Discrimination and stigma were also prevalent experiences, in terms of both aspects of identity, and examples were provided of the intersections of these and other protected characteristics resulting in specific forms of marginalisation. For example, the respondent who described her mental health condition being reduced to her sexual orientation, and finding that her partner, who attended appointments with her for support with communication, was not accepted as such by staff.

Something of a 'hierarchy' of discrimination was expressed by some respondents. For instance, Deaf individuals expressed this aspect of their identity as a stronger and more important healthcare access barrier than their LGBTQ+ identity as compared with hard of hearing individuals. Likewise, a person of colour reported that they were more conscious of the barriers they faced related to responses to their skin colour than they experienced due to being deaf or LGBTQ+. Further engagement is needed to explore this set of experiences and the meanings of this

for improving inclusion. However, this pattern is likely to indicate a splitting off of different aspects of identity depending on the level of acceptance and safety relating to each characteristic in different settings. For instance, the splits between hearing and Deaf LGBTQ+ communities, and white and PoC LGBTQ+ communities mean that a Deaf LGBTQ+ person may feel the need to 'downplay' their Deaf identity to 'fit in' in with a mainstream LGBTQ+ hearing culture. Likewise, an LGBTQ+ person of colour may experience pressure to minimise this aspect of their identity to feel safer in white-dominated LGBTQ+ spaces.

Inclusive information resources were highlighted as an unmet need, particularly with regard to BSL translation, which was also found to be a barrier for Deaf LGBTQ+ community members when engaging with the online survey. This, along with the difficulty of integrating different aspects of identity in hearing-centred LGBTQ+ spaces (of which Switchboard is currently one) may go some way in explaining why no Deaf LGBTQ+ community members chose to participate in a BSL-interpreted 1-1 interview with a (hearing) member of Switchboard staff, and indicates a need for work around Deaf inclusion at Switchboard.

However, something the survey did not record was the felt importance of each different barrier. This will be a helpful addition for future engagement, to understand not only the prevalence of particular issues, but the degree of impact they have with regard to being able to reasonably access services. For example, there may be barriers which are less common, but which are highly or absolutely exclusionary for individuals, which are not being highlighted as strongly in the data. This may help to highlight the needs of individuals of intersectional minority identities, who may be quantitatively under-represented, but whose experienced barriers and challenges may also be proportionally greater.

Recommendations

Brighton & Hove City Council and Brighton & Hove CCG

6. **Provide awareness training for frontline healthcare staff**, including reception teams, in D/deaf, HoH and LGBTQ+ awareness. This should target raising staff awareness of D/deaf/HoH and LGBTQ+ issues, including intersectional points of marginalisation; challenging stigma, stereotypes and discriminatory practices, particularly around heteronormativity and cisnormativity.
7. **Provide online booking for appointments and receiving test results, e**nsuring that online systems properly reflect the person's correct name, pronouns and titles (following on from the April 2018 Monitoring Engagement Report Recommendations)
8. **Ensure Deaf inclusion is built into service planning, including ring-fencing budget for BSL interpretation,** as part of Brighton & Hove City Council's commitments under pledges 1 and 2 of the British Deaf Association's BSL Charter[7]. In order to do this, the council should plan well ahead on future engagement (such as online surveys) in order to receive

[7] Brighton and Hove City Council signed the British Deaf Association's British Sign Language (BSL) Charter in 2017, committing to five pledges:

6. Consult formally and informally with the local Deaf community on a regular basis
7. Ensure access for Deaf people to information and services
8. Support Deaf children and families
9. Ensure staff working with Deaf people can communicate effectively using British Sign Language
10. Promote learning and high quality teaching of British Sign Language

recommendations from the Deaf Services Liaison Forum regarding which surveys BSL interpreted clips should be funded for as a priority, so that costings can be better determined and allocated appropriately.

9. **Make intersectional inclusion a priority in patient participation groups,** particularly with regard to including members of the Deaf, deaf and hard of hearing and LGBTQ+ communities. Explore mechanisms for including the input of these voices when ongoing in-person attendance at PPGs is not viable.
10.
    a. **Offer visual cues for appointments and information in waiting areas** (e.g. screens showing patient name calls)
    b. following on from the Monitoring Engagement Report Recommendations, **continue to develop protocols to ensure that information is accurate and sensitive to trans patients, with regard to correct name, titles and pronouns.**

Switchboard

4. **Secure Deaf-awareness and introductory BSL training** for frontline staff to ensure a good level of D/deaf and HoH awareness and competence
5. **Seek to improve LGBTQ+ Deaf inclusion and representation at Switchboard by ensuring the upcoming Switchboard Community Steering Group (**as part of the Autumn 2018 CCG Engagement Topic) **is meaningfully Deaf inclusive**, thereby ensuring this community is represented in organisational decision-making and community engagement processes.

6. **Continue to develop relationships with Deaf organisations**, to improve signposting relationships and inform future engagement.

References

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