Sexual Orientation, Gender & Trans Status Monitoring

Beyond 'ticking the box'

Consultation with Healthcare Providers and the LGBTQ+ Community

Engagement and Consultation Report

April 2018

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

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

Table of Contents

Executive Summary

The Consultation

LGBT HIP consulted with healthcare providers and the LGBTQ+ community about monitoring sexual orientation, gender and trans status. We held one-to-one meetings with several GP Practice Managers and conducted an online survey for primary and secondary healthcare providers, including clinical and non-clinical staff, across Brighton and Hove. We also conducted a focus group and an online survey engaging the Brighton and Hove LGBTQ+ community.

"Brighton and Hove are areas where there is a high and visible community of [LGBTQ+] people and we as service providers have a greater responsibility to make an effort to meet their needs." – Healthcare provider survey response

Background

This consultation came in timely response to NHS England's new **Sexual Orientation Monitoring (SOM) Information Standard**, published in October 2017, which sets out how health and social care providers should monitor sexual orientation going forward.

Gender and Trans Status are different characteristics and should be monitored separately

This Information Standard only covers sexual orientation, however, not gender and trans status monitoring. We therefore saw an opportunity to learn about healthcare providers' and LGBTQ+ community members' experiences, preferences and challenges with monitoring across all three characteristics.

Key Findings: Healthcare Providers

- *While the valuing of monitoring was reportedly high, the survey and meetings suggested that the benefits and purposes of monitoring are not yet widely understood by healthcare providers*
- *Nearly 7 in 10 healthcare professionals were not aware of the SOM Information Standard*
- *Services need more guidance and information about monitoring good practice*
- *Healthcare providers require particular guidance on monitoring these characteristics, due to their potential clinical, as well as demographic, significance*

SOM Information Standard Key Facts

In partnership with the LGBT Foundation, NHS England introduced a Sexual Orientation Information Standard, outlining how health and social care services should record data

NHS England has set a target for 100% compliance with these guidelines throughout health and social care services by April 2019

Monitoring sexual orientation is not mandatory under the standard, but any services that *do* monitor, *must* use the guidelines provided

The Information Standard sets out how services should *record* information about sexual orientation. However, services may offer different or additional options on their own monitoring materials when *collecting* the data, *provided that these responses can accurately map over the options provided by the SOM Information standard at the point of recording.*

- *Understanding and awareness of LGBTQ+ health inequalities was an area in need of attention, as was awareness of sexual and gender diversity in general - including an understanding of the distinctions between sexual orientation, gender and trans status*
- *Discomfort with monitoring sexual orientation, gender and trans status was prevalent, often due to a perception that asking about these characteristics was intrusive or invasive*

Nearly 7 in 10 respondents were not aware of the new NHS Sexual Orientation Monitoring Information Standard

- *IT systems are currently a key challenge to capturing gender and sexuality diversity accurately, with clinical systems offering incomplete and sometimes unclear or inappropriate options. Inconsistencies in recording options across clinical systems also posed a barrier to clear communication about patient characteristics between different services.*

KEY FINDINGS: LGBTQ+ COMMUNITY

- *LGBTQ+ people face significant barriers to sharing monitoring information, both in terms of a lack of options that sufficiently reflect LGBTQ+ diversity, and also the context and way in which monitoring questions are asked, which are not always LGBTQ+ inclusive. Trans and non-binary people, in particular, face additional barriers.*
- *Concerns about clinical staff in healthcare settings making assumptions about sexual practices and partners, and giving inaccurate health advice on this basis, is a key barrier for many LGBTQ+ people to sharing monitoring information.*
- *When asked respectfully, inclusively, and with an understanding of the reasons, most LGBTQ+ people are glad for the opportunity to share information about their sexual orientation, gender and trans status.*
- *LGBTQ+ people are less confident sharing monitoring information in council than healthcare settings, so additional efforts are required in council settings to ensure they are LGBTQ+ inclusive in general, as well as in their monitoring practices.*
- *Individuals are likely to respond differently depending on how the data will be used, so those collecting the data should be clear about precisely what it is they want to know, and why.*
- *Sexual orientation, gender and trans status monitoring work best and are most meaningful – personally, demographically and clinically - when done together. LGBTQ+ community members said all three characteristics should be recorded in conjunction in order for any one of these individual characteristics to be meaningfully understood: personally, demographically and clinically.*

"Are these questions being asked for the patient, or is it just so that the GP can tick another box? If it isn't for the person being asked, for their wellbeing, then why would they answer?" – LGBTQ+ Focus Group Participant

Recommendations

These recommendations have been developed out of the findings of the online survey and focus group with the LGBTQ+ community and the online survey and one-to-one meetings with healthcare providers. It is hoped that the following recommendations may act as a guide for the CCG in the development and implementation of monitoring practices for sexual orientation, gender and trans status. The recommendations are divided into those relevant to getting ready for implementing SOM (NHS England expects 100% compliance by 2019), and those for carrying out monitoring of different characteristics.

Getting ready for SOM Recommendations

1. Inclusion Award Scheme

Brighton and Hove CCG should commission Switchboard (through LGBTQ HIP) in partnership with the Trans Alliance to develop the LGBTQ Inclusion Award. The inclusion award could then provide a 'bench mark' for those health settings being compliant with NHS Sexual Orientation monitoring (NHS target is 100% compliance by 2019). As monitoring sexual orientation is part of the scheme's basic (bronze) accreditation – the Award could be used as a lever to implement monitoring in participating healthcare services throughout the city. Monitoring-specific training and/or information resources could also be developed and delivered through this.

2. LGBTQ+ and Monitoring Awareness Training

The CCG should support the development and delivery of specific LGBTQ+ awareness and monitoring awareness training. This should be compulsory for clinical *and* non-clinical staff as standard in healthcare settings.

3. IT Infrastructure Support

The CCG should support and guide key IT system upgrades to accommodate the accurate recording of data for sexual orientation, gender and trans status monitoring purposes. The necessary IT system updates for SOM present an opportunity to upgrade for gender and trans status monitoring at the same time. In addition to sexual orientation monitoring options as provided by the SOM Information standard, this should also include a 'non-binary' option for gender, and a separate question/answer pair for trans status. In support of these updates, a gender-neutral 'Mx' title option should be available, and pronouns should be recorded as standard.

4. Harmonise data collection and communication between health trusts

The CCG should work to ensure that the updates to data collection and recording practices are shared and communicated between different health trusts, to ensure that different systems are able to share patient data in a harmonised fashion.

5. Incentivise monitoring

As the SOM standard is not mandated by NHS England, the CCG should consider ways in which it can incentivise monitoring with healthcare providers. Any incentives could be communicated as part of a wider monitoring awareness campaign, as in recommendation 7.

6. City-wide LGBTQ+ Demographic Data

The CCG should ensure that monitoring data gathered by health and social care providers is collated to form a base of city-wide demographic data on LGBTQ+ communities.

7. Monitoring awareness campaign

The CCG should commission Switchboard, through LGBTQ HIP, to coproduce with patients and health professionals an awareness raising campaign highlighting sexual orientation monitoring – this would be a future engagement topic as part of the TSIP commission. This would use the target of 100% compliance with the SOM Information Standard by April 2019 as a benchmark and could galvanise around an aim to position Brighton and Hove as a national 'best practice' example of gender and sexual diversity monitoring.

Trans-specific Recommendations

8. Protocol for changing clinical records of trans patients

The CCG should develop and implement a clear protocol for dealing with the clinical records of patients who have undergone gender transition, and who have a new NHS number and corresponding clinical record, to ensure important clinical information is not lost from a previous record. This guidance should be developed in consultation with the trans and non-binary communities in Brighton and Hove. This should include the development and distribution of information and guidance resources for the protocol. The CCG should also consider offering specialised training to healthcare providers in this area.

Monitoring Guidance Recommendations

General Monitoring Guidance

Excellent 'good practice' resources for monitoring sexual orientation, gender and trans status already exist. Links to some of these are provided at the end of this report. However, several points of guidance for general good monitoring practice emerged through engagement and consultation with the LGBTQ+ community and healthcare providers.

- **Services should take the opportunity to update their gender and trans status monitoring at the same time as SOM**
  It will be most cost and time effective for service providers to update IT systems and monitoring resources for gender and trans status monitoring at the same time as sexual orientation monitoring, to meet the new SOM Information Standard Guidelines. In addition to the practical benefits of this strategy, a strong finding of the consultation with the LGBTQ+ community was that these characteristics were most valuably understood when all were recorded, and that they were less meaningful – personally, demographically, and clinically – when taken in isolation.
- **Re-framing monitoring as mutually beneficial information sharing rather than 'taking' information**
  In line with research by the Human Rights Commission on monitoring, it would be beneficial for services to re-frame equality and diversity monitoring in a way that recognises the mutually beneficial and transactional nature of information sharing with services. It should be acknowledged that sharing this information is not compulsory for service users/patients, and that the process exists for the latter's benefit should be at the heart of conducting and communicating about monitoring.
- **A need for re-framing SOGITS from being an 'LGBTQ issue' to an 'everyone issue'.**
  While it is essential that it be highlighted and addressed that LGBTQ+ people face specific health inequalities and barriers to inclusion, it must also be understood that sexual orientation, gender and trans status (whether a person's gender is cis or trans) affect and are relevant to *everyone*. Heterosexism and cissexism lead to a perception that being

heterosexual and cisgender are 'neutral' qualities, and that monitoring is therefore only relevant to those who fall outside of this perceived 'norm'.

- **Healthcare providers must be clear about whether they are gathering data for equality and diversity purposes or for clinical information**
  Individual services need to think carefully about *why* they are asking specific questions. They must have a clear understanding of what information they are looking to capture by asking specific monitoring questions, and this reason must be communicated to respondents. Furthermore, services should monitor on multiple occasions, not just at initial service engagement. Ideally, there would be a 'self-service' option for individuals to amend their own details online.
- **Healthcare providers should avoid making assumptions about sexual practices and partners, or about sexual health and family planning needs**
  They should avoid doing so even when they have information about a pesron's sexual orientation, gender and trans status. For example, lesbian patients may still require contraception and family planning advice, and can still become pregnant. Clinical advice related to sexual health and family planning should be offered in a person-centred way.

Sexual Orientation

- Services should consider including Queer and Asexual as options
- A free text field space should be provided to name one's actual sexual orientation in addition to selecting 'Other'
- Services should be clear about the specific meaning of 'sexual orientation' as related to identity and affiliation rather than sexual practice/ behaviour
- Healthcare professionals should avoid making assumptions about sexual practices and partners, even where sexual orientation, gender and trans status are known. They should instead speak with each individual to understand their specific situation and needs.

Gender and Trans Status Monitoring

- Non-binary should be included as an option
- This should be supported by an 'Mx' title option
- Binary gender options should include an explicitly trans inclusive statement
- It should be made clear that it is (self-identified) gender rather than (assigned at birth) sex that is being requested, when this is the case
- A question about trans status is important, but should always be asked separately from a question about gender. Gender and trans status should not be conflated, and 'transgender' should not be an option under 'sex' or 'gender'.
- A question wording that describes one's relationship to one's gender is preferable and more inclusive as compared to one that asks outright about identity and status – e.g. "Do you identify with the gender you were assigned at birth?" rather than "Do you identify as trans?"

Further guidance

- Intersex Status has been a widely neglected area in monitoring. It was not possible to adequately address within the scope of this consultation and requires further investigation
- Pronouns should be included in monitoring materials as standard
- An 'Mx' title option should be included in monitoring materials, to support the addition of a non-binary option within gender monitoring

Overview

It is widely documented that LGBTQ+ continue to face significant health inequalities and barriers to access and inclusion in health and social care settings [citation/ stats]. Monitoring has been recognised as a key component in understanding the health and social care needs of marginalised groups. While it is now commonplace for services to monitor characteristics such as age and ethnic origin, sexual orientation, gender and trans status have not been widely monitored. As a result, there is a dearth of statistics on the numbers and specific health needs of LGBTQ+ people.

Recording sexual orientation, gender and trans status will allow policy makers, commissioners and providers to better identify health risks and will help support targeted preventative and early intervention work to address the health inequalities LGBTQ+ people.

Significant strides are being made, however. In October 2017, NHS England released a Sexual Orientation Information Standard, which sets out how health and social care services should monitor sexual orientation. However, this does not address gender or trans status. In response to this gap in research, LGBT HIP took the opportunity to consult with the LGBTQ+ community and healthcare providers about practices, preferences and attitudes towards monitoring for all three characteristics.

Method

We utilised a range of methods for the two branches of the consultation:

Healthcare Providers

- **One-to-one meetings** with three GP surgery Practice Managers and other relevant team members
- **An online survey** for primary and secondary healthcare staff/professionals, including clinical and non-clinical

LGBTQ+ Community

- **A focus group** exploring preferences, needs and attitudes in relation to monitoring
- **An online survey** open to all LGBTQ+ identifying people who live, work, study or socialise in Brighton and Hove

Background

Several previous HIP reports have demonstrated the need for health and social care services to take actions to better understand and respond to the needs of their LGBTQ+ patients and service users (Kitemark, 2016; Changes to Primary Care, 2015; LBQ Women's Health, 2015). With the introduction of the SOM Information standard, NHS England has recognised monitoring as a key strategy for addressing and reducing health inequalities. The Inclusion Award project, which LGBT HIP piloted in 2017, held monitoring sexual orientation as a criteria in its basic 'bronze' category of the award.

Equality Act 2010 and Public Sector Equality Duty (PSED)

Monitoring sexual orientation, gender and trans status can be a way of services demonstrating that they meet the requirements of the Equality Act 2010 and attendant PSED.

"Sexual orientation", "sex" and "gender reassignment" are three of the nine protected characteristics defined by the Equality Act 2010. The PSED (section 149 of the Act) contains a legal obligation for all public sector bodies to pay due regard to the needs of lesbian, gay, bisexual and trans people in the design and delivery of services and ensure (and be able to demonstrate) that

people are not discriminated against based upon their sexual orientation or trans status. Under the PSED, public services have a responsibility:

- To eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the Act
- To advance equality of opportunity between people who share a protected characteristic and those who do not
- To foster good relations between people who share a protected characteristic and those who do not

Sexual Orientation Monitoring Information Standard

Working closely with key stakeholders including NHS Digital, the Lesbian Gay Bisexual and Trans (LGBT) Foundation led the work to develop a Sexual Orientation Monitoring Information Standard on behalf of NHS England. The SOM information standard provides a consistent mechanism for recording the sexual orientation of all patients/service users aged 16 years across all health services in England. It will also cover local authorities with responsibilities for adult social care in all service areas where it may be relevant to record this data using a standardised format.

This standard provides the categories for recording sexual orientation but does not mandate a collection. Furthermore, "the standard is intended to outline how users will map data, rather than how they should record it; it describes the output rather than the input." As such, individual services may choose to offer different sexual orientation options at the point of data collection, provided they can accurately map over the categories provided by the information standard, which are as follows:

"Which of the following options best describes how you think of yourself?

1. Heterosexual or Straight

2. Gay or Lesbian

3. Bisexual

4. Other sexual orientation not listed

U. Person asked and does not know or is not sure

Z. Not stated (person asked but declined to provide a response)

9. Not known (not recorded)

The SOM has been based on research conducted by the Office for National Statistics (ONS) and the Equality and Human Rights Commission (EHRC), and on current practice by those organisations which monitor sexual orientation.

This is a significant milestone in promoting Lesbian Gay Bisexual equality in England.

NHS England suggest 50% compliance by April 2017 (the time of submitting this report) and 100% compliance by April 2019.

The 'Information Standards Notice' (ISN) and other official information relating to the Standard can be found on the Information Standard page

LGBT Foundation has developed a "Good practice guide to monitoring sexual orientation"

Gender and Trans Status Monitoring

While the SOM Information standard looks specifically at Sexual Orientation, there is currently no national Information Standard for monitoring gender or trans status. Previous HIP Reports have demonstrated a need for greater inclusivity with regards to gender diversity, particularly for trans and non-binary people, in healthcare and council services, particularly the LGBT HIP LGBTQ Kitemark Consultation (now known as 'The Inclusion Award'). In response to this need, within this consultation, we have taken the opportunity to extend our research and engagement to encompass gender identity and trans status as well as sexual orientation.

The relationships between sexual orientation, gender and trans status are complex and nuanced. However, for the purposes of equalities and inclusion work, it is important to understand that gender and trans status are *related but distinct* characteristics.

LGBTQ+ Community: SOGITS Monitoring Consultation

Consultation summary

As part of engagement with the Brighton and Hove LGBTQ+ communities, we conducted a focus group and an online survey to learn about community members' experiences and preferences in relation to sharing monitoring information about sexual orientation, gender and trans status.

Focus Group

The aim of the focus group was to engage community members and stimulate discussion on the significance of monitoring, generate in-depth qualitative data about community members' views, and to draw from this in designing a survey to capture a broader base of quantitative data about preferences, attitudes and experiences.

Ten people attended the focus group, which was held in the evening at an accessible, central location. The group was co-facilitated by an LGBT HIP worker and a facilitator from the Trans Alliance. Participants were offered £10 in thanks for their contribution, and an offer was made to cover travel expenses to increase accessibility.

The group ran for two hours and explored participants' preferences around monitoring questions and answer options, as well as the factors that were important in influencing their comfort levels sharing monitoring information, through group discussion and reflection exercises. The discussion included exploration of attitudes and preferences in relation to monitoring in healthcare specific settings, as well as in general.

The focus group was structured into two sections:

I. Monitoring questions and answer options: Exploring preferences with regard to monitoring questions and answer options – how these are worded and different kinds of terminology used
II. General monitoring issues: Discussing experiences and preferences in relation to the environmental and relational factors that influence individuals' comfort levels with sharing monitoring data

Demographics

Nine out of ten participants completed monitoring forms. One participant needed to leave the group before monitoring forms were distributed at the end.

Neighbourhoods

7/10 participants were based in the central Brighton and Hove areas, and two in other areas:

Postcode	*Participants*
BN1	1
BN2	3
BN3	3
BN9	1
SO43	1

Sexual Orientation

A fair diversity of sexual orientation was represented. Focus group participants identified their sexuality in the following ways:

- Queer (3)
- Lesbian (2)
- Unsure (1)
- Demi-femsexual (1)
- Androsexual (1)
- One said they would not define their sexuality in any way

Age

A wide age range was represented in the focus group, which was open to participants aged 18+, as follows:

- 25-34 (2)
- 35-44 (3)
- 45-54 (2)
- 55-64 (1)
- 75+ (1)

Gender

A strong range of gender diversity was represented in the focus group. Participants identified their gender in the following ways:

- Woman (3)
- Agender (2)
- Non-binary (2)
- Man (2)

Trans status

A high number of focus group participants' genders did not match the gender they were assigned at birth. When asked "Does your gender match the gender you were assigned at birth?":

- Said 'No' (6)
- Said 'Yes' (3)

Intersex status

Eight participants said they did not have an intersex variation. One participant said they were unsure.

Disability

A high number of participants (8/9 who completed monitoring forms) said they live with a health condition, impairment, learning difference or neurodivergence that shapes their day-to-day activities. Only one participant did not have any known condition, impairment, learning difference or neurodivergence:

- Long terms illness (2)
- Mental Health difficulty (6)
- Physical impairment (1)
- Neurodivergence (4)
- No known condition (1)

Religion/ faith/ spirituality

Most participants identified as atheist (5) or not having a religion (3), and one identified as Christian.

Ethnic origin

One participant was from a BAME background: Six participants were 'White British', one was 'White Irish', and one was from an 'Other Mixed Background'.

Discussion: Key themes

Personal, demographic and clinical significance

Through the course of the focus group discussion, three key areas of significance emerged in relation to individuals' relation to monitoring. We have characterised these as 'personal', demographic' and (in healthcare settings) 'clinical'.

Personal significance relates to individuals' wishes to be able to accurately represent themselves and be seen as who they are by the services they engage with.

Demographic significance relates to individuals wishes to have the group to which they belong meaningfully represented and responded to, usually for purposes of equality and diversity monitoring, for example to identify and understand health inequalities and inclusion issues.

Clinical significance relates to individuals wishes to have their sexual orientation, gender and trans status properly understood in relation to the specific healthcare needs they may have in relation to these characteristics.

Monitoring questions and answer options

In the first half of the focus group, we provided an overview of the purpose of the engagement, monitoring in general, and the current context in relation to the Sexual Orientation Monitoring Standard.

Sexual Orientation Monitoring

We presented participants with the current question and answer options as provided by the SOM Standard, and opened up a general discussion on the strengths and weaknesses. It was explained that although these options are now fixed, individual services may choose at their discretion to provide additional options or different wordings, but that they would have to map any data collected in the following way:

Which of the following options best describes how you think of yourself?

1. Heterosexual or Straight

2. Gay or Lesbian

3. Bisexual

4. Other sexual orientation not listed

U. Person asked and does not know or is not sure

Z. Not stated (person asked but declined to provide a response)

9. Not known (not recorded)

The following key themes emerged:

"Which term best describes how you think of yourself?" accepted as a question

There was universal positive agreement in the group regarding the above question wording. In particular, it was valued that the question acknowledged that the terms provided were inexhaustive.

> *"Acknowledging that there might be none of them that are perfect, but asking 'which is the closest?' I quite like that"*

Confusion over the specific meaning of 'Sexual Orientation' in a monitoring context

Several participants expressed confusion over what specifically was being asked by the sexual orientation question: specifically, whether this was to do with identity or sexual practices. Particularly in healthcare settings, participants felt specific clarification was needed. Due to the clinical nature of most information shared, it was perceived that clinicians would be asking about sexual orientation in order to discern which sexual practices patients would be engaging in, and what healthcare advice or services they would or would not need in accordance with these.

Assumptions are a key concern, especially those about sexual practices

Several participants made the point that clinicians should never make assumptions about sexual practices based on perceived or reported sexual orientation, gender and trans status. It was discussed that sexual identity, orientation and practices are nuanced, complex and highly individual, and that assumptions about specific sexual behaviours or partners would be likely to miss information that had clinical and personal significance for the individual. Participants also expressed discomfort at the thought of clinicians wondering about the sexual practices they engaged in, and a need for clear boundaries around what was/ was not being asked and why, so that the individual felt adequately informed to decide what information to share.

Trans and non-binary exclusion

Through the discussion, several trans, non-binary and agender participants shared concerns that there were no named sexual orientations they could choose from that would adequately describe their orientation, as these were based on binary gender assumptions. Dissatisfaction was expressed that the only option available to them would be to choose 'Other sexual orientation not listed', which was felt to be 'Othering', and to deny an opportunity to share personally, demographically and – in a healthcare setting – potentially clinically significant information.

> *"I find it very difficult to answer the sexuality, so I would have to put other sexuality, because sexuality in those terms are linked to your gender and if I don't have one, what's my sexuality?"*

'Gay' and 'lesbian' should be presented separately, not within the same option

It was noted that 'gay/ lesbian' being placed together in a single option might lead to incorrect assumptions about someone's gender, based on a staff member or clinician's perception of the person's appearance. This was a particular concern where gender was not properly monitored.

In addition to this mis-reading having personal significance for individuals, there was also a concern that, in a healthcare setting, this could result in inappropriate sexual health advice being offered, based on incorrect assumptions of sexual practices and partners.

"PEOPLE GET REALLY CONFUSED ABOUT WHAT STRAIGHT AND GAY MEAN IN RELATION TO TRANS PEOPLE [...] THE UNDERSTANDING ISN'T THERE FOR A LOT OF PEOPLE"

Gender *and* sexual orientation should be monitored together

Related to the above point, participants said it is important to ask questions about *both sexual orientation and gender* in order for the information to be personally, demographically and clinically meaningful. It was noted that this was particularly important for trans and non-binary people, whose genders and/or sexual orientations are often not widely understood or accepted in the mainstream.

"I think it's quite difficult to think of [the sexual orientation question] in isolation from the gender question […] ***for people that are non-binary or trans to describe your sexual orientation in these kinds of terms is quite difficult at the best of times****, so I think personally I would like to see the two questions asked together and that it was going to somebody who understood what that meant, as well"*

"ONE BOX I'D CONSIDER TICKING IS 'GAY OR LESBIAN'. I'D BE TICKING IT AS GAY, BUT THEY MIGHT ASSUME THAT I MEAN LESBIAN, SO THAT'S WHY THE GENDER BIT MATTERS"

'Other' option as 'othering'

Although many participants expressed dissatisfaction with what they felt to be resorting to the 'Other' option, it was agreed that the inclusion of this option at all reflected a step forward from offering only 'gay/ lesbian' or 'heterosexual/ straight'. However, several participants noted that the term 'other' can have painful connotations for communities that have been historically marginalised and 'othered' by mainstream heterosexual and cis-gender orientated culture.

"There's a whole idea of 'the other' being a bad thing […] The other sometimes has a negative connotation, to feel other is not always a nice feeling, so to tick 'yes I am other' might not be a very nice feeling"

Need for an opportunity to self-describe in addition to choosing 'Other sexual orientation not listed'.

Participants universally felt that it would be important to have an opportunity to self-describe in addition to selecting 'Other'. It was felt that, on its own, this category was somewhat alienating for individuals on a personal level, that it missed an opportunity to capture key demographic information about other statistically significant sexual orientations (particularly queer and asexual), and that it did not provide any meaningful information that might have clinical implications for the individual.

Concerns were also raised that staff and clinicians would make unwelcome assumptions about an individual's sexual orientation and practices if their actual self-described orientation was not named and recorded.

"I'm non-binary transmasculine – I wouldn't know *how to answer that question.* ***I think I'd end up ticking 'Other sexual orientation not listed' and that, I would feel, wouldn't really communicate my needs or my situation. All that says is 'your boxes don't fit me' but that doesn't explain why or how*** *– so I think it*

would be really important to have a space where you could expand on your answer."

"[IF THERE'S NO OPPORTUNITY TO SELF-DESCRIBE IN ADDITION TO 'OTHER'] IT LEAVES IT TO YOUR GP AGAIN TO ASSUME WHAT YOU ARE AND WHAT YOU'RE DOING"

Need for inclusion of 'Asexual'

It was noted that the absence of sexual orientation, as in the experience of asexual people, should also be recognised as a legitimate and prevalent relationship to sexual orientation, and be duly represented on monitoring materials. 'Asexual' would be a welcome answer option.

Need for inclusion of 'Queer'

It was stated that queer is now a common and prevalent orientation, and that it is also a more widely used ad accessible term for many trans, non-binary and agender individuals. 'Queer' would be welcome as an answer option.

'Prefer not to say' option valued

Several participants shared that they valued the option not to answer by choosing 'prefer not to say' or an equivalent. It was expressed that this would provide a welcome option for "anonymity".

Gender Monitoring

Binary gender options

We presented participants with a range of possible gender options for the traditional binary gender options usually provided. The first two options were based on recommendations from the LGBT Partnership, and included:

1. Gender and sex terms with explicit trans inclusion
    - *[Woman/ female (including trans woman) and Man/ Male (including trans man)]*
2. Sex term with explicit trans inclusion
    - *[Female (including trans woman) and Male (including trans man)*
3. Gender term only
    - [*Woman and Man]*
4. Sex term only
    - *[Female and Male]*

Participants were invited to consider their preferences and write these down on post-it notes, along with any other relevant comments. These were then collated and discussed as a group. The current views and themes emerged:

A gender monitoring question should be explicitly trans inclusive

It was universally agreed by trans and non-binary participants that an explicitly trans inclusive option (such as options 1 and 2) would be valued.

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*"…**to make it clear when they're saying male that that includes trans male, to me that makes it feel a little more inclusive** in that it's acknowledged that we treat you equally whether you're a cis male or a trans male. **To me that feels quite affirming**"*

Monitoring should not separate trans from cis-gender gender options

The somewhat prevalent practice of offering 'transgender' as a separate option to 'male' and 'female' on many monitoring forms was discussed, and this was universally acknowledged as problematic. Participants said separate questions for gender and trans status should be offered.

> *"**Instead of asking 'are you trans?' keep it broad.** So you're not saying if you're a cis-man you're a man but if you're a trans man you're not a man. **Keep it gender neutral in a separate question**"*

"I CERTAINLY WOULDN'T WANT TO SEE IT WHERE YOU HAVE TWO SEPARATE OPTIONS FOR MALE VERSUS TRANS MALE- THAT MIGHT BE THE WORST CASE"

Self-identified gender should be emphasised

It was discussed that, particularly for trans individuals, there can sometimes be a confusion over whether they are expected to provide their (self-identified) gender, or their 'biological sex' as assigned at birth, or as perceived by the medical establishment. This can be a distressing and confusing experience, and any gender monitoring should therefore make it clear that it is the individuals self-identified gender that is being requested. Trans status should be asked as a separate question so as to avoid the implication that trans individuals' status as men or women is not in some way less legitimate than their cis-gender counterparts'.

> *"[Depending on why you are being asked] in some contexts you might provide one gender, and in other contexts you'd give another gender. […] until you've started going through the process of reassignment you're under this sort of weighing one thing against the other."*

Beyond the binary gender options

We then opened up the discussion to which additional gender options could be offered. The following key themes emerged:

'Non-binary' option should be included

The need for non-binary gender/s to be recognised and form a part of standard monitoring recurred as a theme throughout the focus group. Several non-binary participants voiced that this term would have important personal and demographic/ community significance.

"JUST THAT IN ITSELF, TO SEE THAT QUESTION [ABOUT NON-BINARY] ON A FORM, WOULD FEEL LIKE: OOH, SOMEBODY SEES US! THIS IS NICE! JUST TO HAVE THAT SPACE OF IT BEING VALIDATED WOULD BE USEFUL"

It was also agreed that the term could be a useful 'umbrella' for a range of identities (such as genderqueer, genderfluid, and other gender orientations that sit beyond the classical binary).

> *"I think it's important to have that space for non-binary. […] **Non binary can be an umbrella term for so many different identities.***

I was sort of torn as to whether it would be useful to list all the different non-binary identities […] whether it's useful to list them all out or whether actually it's more helpful just to have non-binary as the category […] ***because what you really want is to show, not to put too fine a point on it, that non-binary people actually exist****, because a lot of people still think we're just making it up as we go along.*

Because there's no data collected at all on non-binary people it's very difficult to make statements [about our needs] in the same way people might about, say, 'the trans community has these and these issues'. If you're not acknowledged on the form at all, then where do you even start?"

The dilemma over whether to aim for increased inclusion and greater personal significance by offering a wide range of gender options, or offering 'non-binary as an umbrella term, which would capture greater demographic significance, was discussed:

"In funding terms, with the spectrum of non-binary, if you have every tiny definition it splits it up, it's a bit like splitting the vote. ***If you have it just clumped as non-binary, you have bigger representation, but then you're not able to describe the nuance of your identity."***

'Agender' option should be included

It was acknowledged, however, that 'agender' (an absence of gender identification) requires representation as a separate experience from non-binary gender.

"I WOULD PREFER AGENDER TO BE THERE – FOR ME THAT CAN BE SEPARATE TO NON-BINARY"

A space for self-description or additional information should be included

It was noted that, for clinical purposes, a space to self-describe or provide additional information would be valued for individuals who are going through gender transition at the time of monitoring.

'Sex' monitoring practices

It was noted that, rather than gender, many monitoring forms instead ask for 'sex', and that this therefore warranted discussion as part of a conversation about gender monitoring practices. It was also discussed that the distinctions between 'sex' (as commonly referring to biological and physiological sexual characteristics) and 'gender' (as referring to social, cultural and psychological/ emotional identification) are not widely known or understood, including in the health field.

Generic 'Sex' monitoring questions are often not inclusive for trans and non-binary people

"I WOULDN'T KNOW WHAT TO PUT FOR 'SEX'. I'M NON-BINARY TRANSMASCULINE AND I'M CHOOSING TO MEDICALLY TRANSITION, SO I DON'T KNOW WHAT I'D PUT FOR SEX."

The question of sex, it was acknowledged can be highly nuanced, complex and individual and is an issue that many trans and non-binary people grapple with. As such, I may be stressful to be presented with a form that demands one make a clear and binary statement about one's sex.

Several trans and non-binary participants shared that questions requesting 'sex' could be confusing, limited in personal meaning, and difficult to answer. This is because it was not clear whether they are being asked:

- Their assigned sex at birth
- Their current sex as appears on medical records (regardless of whether surgical and/or hormonal or other medical intervention has taken place as part of transitioning)
- Their self-identified sex, which may not match current medical records

It was raised that those monitoring should be clear about specifically what it is they would like to know based on any question, but particularly with regard to sex and gender; whether they are aiming to understand individuals' embodiment/physiology or their identity, as this will influence whether the person's choice of whether to respond, and which answer to provide.

"For the trans/ NB communities it would probably make more sense to put 'assigned sex at birth' […] but do they need that information in the first place? ***There are issues about assigned-female-at-birth versus assigned-male-at-birth bodies that GPs might need to know, but it's a different question from gender identity, so that's all quite confusing"***

It was also noted that these questions can have important clinical significance for individuals, so it is particularly important to get it right. For example, there were concerns expressed about trans individuals not being invited for necessary routine health checks (e.g. for prostate cancer for trans women and cervical smear for trans men) once they had changed their sex on their medical records.

"IF YOU CHANGE YOUR GENDER WITH THE NHS, I DON'T THINK YOU GET REMINDERS ABOUT THOSE THINGS [ROUTINE CHECKS] ANY MORE"

One participant shared an anecdote about a transmasculine nonbinary friend going for a cervical smear test about being gendered as female throughout the process.

Trans Status Monitoring

In the discussion regarding trans status monitoring, we offered three options of question wording, based on good practice as shared by the LGBT Partnership and resources created by TransEdu Scotland. They were:

1. "Do you identify with the gender you were assigned at birth?"
2. "Do you identify as trans or have a trans history? "
3. "Do you identify with the gender associated with the sex you were assigned at birth?"

We then opened up the group to discussion. The following key themes and responses emerged:

A question about trans status is welcome and needed

Throughout the discussion it was repeatedly emphasised that trans status is an important category to capture, and that participants would be happy to be asked about this provided the question was asked in an inclusive and respectful manner.

"For those wanting to disclose their trans status it's important to have that option because their health needs will be different depending on whether they're cis or trans"

"It needs to be asked"

Trans status should be asked separately from gender

Reflecting points raised in the discussion on sexual orientation and gender monitoring, this point came through again emphatically, upon reflection that many monitoring forms do provide 'transgender' as an option under 'gender' and that this is provided separately from 'male' and 'female', which was recognised as minimising and diminishing of the legitimacy of trans individuals' gender. It was widely agreed that trans status should be asked separately from gender.

"Do you identify with the gender you were assigned at birth?" as a preferred question wording

A general preference for this first option emerged through the discussions. It was noted that the wording 'identify with' was perceived as preferable to and "softer" than 'identify as'. The group found it difficult to articulate why this difference was important, but this was a shared feeling.

"I prefer the question 'do you identify with the gender you were assigned at birth?' instead of 'are you transgender?' because then you're not having to worry about the question about definitions - you're not throwing a label on someone"

It was also suggested, however, that the word 'identify' by be confusing for some. An alternative wording suggested was:

"Is your gender the same as the one you were assigned at birth?"

Do you identify as trans or have a trans history?

It was suggested that the wording might be considered overly direct and force someone to apply a definition or label to themselves that may not be welcome. A more description-orientated wording, such as that offered by option 1, was favoured, over a state-defining or 'labeling' one.

Do you identify with the gender traditionally associated with the sex you were assigned at birth?

This options was felt to be overly "wordy" and difficult to understand. It was also felt that "the gender associated with the sex assigned at birth" represented an unwelcome assumption of a particular gender being associated with a particular sex.

A 'partially' response option should be offered

One participant raised that they would like a 'partial' response option. It was explained that one's relationship to one's identification with gender assigned at birth can be more nuanced and complex than a simple 'yes/no' binary, and that a question about trans status should allow space for this.

However, it was not discussed if individuals choosing 'partially' would like to be recognised as trans for demographic and statistical purposes. Where this question is being asked for equality and diversity purposes to quantify the numbers of people who might experience marginalisation based on not identifying with the gender assigned at birth, a 'partially' option may therefore lead to an impression of lower numbers of these patients.

Titles and pronouns – including 'Mx' and 'they/them/their' should be recorded

> *"Having the right box ticked gives the new consultant or whoever a clue to the form address and how to treat the patient with respect. That's very important: to leave the patient with dignity by respecting who they are."*

Discussion was also raised over the question of recording correct titles (Mx/ Ms/ Mr, etc.) and pronouns.

There was wide agreement in the group that it was important for there to be a record of individuals' correct pronouns and titles. It was felt that monitoring forms would be the best opportunity to provide this information.

It was noted that pronoun options should include the gender-neutral they/them/their pronouns as well as she/her/hers and he/him/his.

It was also noted that the gender neutral pronoun 'Mx' is not always routinely available, and that this needs to be recognised as an equally essential option than traditional binary-gender-based titles.

It was also stated that this information should be kept in a centralised record so that there wasn't a need to constantly re-introduce oneself with correct pronouns when moving through different surgeries and healthcare departments and services.

General monitoring issues

The second half of the focus group opened the discussion to broader issues and factors that influence people's comfort, confidence and willingness to share monitoring information. The following key views, attitudes and experiences emerged:

Monitoring is important and welcome – as long as the reasons for it are understood

A general theme throughout the discussion was that monitoring in general was welcome – of sexual orientation, gender and trans status – but only if it was understood for what purpose the questions were being asked. This confirms research conducted by the LGBT Foundation which found a 96% acceptance rate for questions about sexual orientation, provided that the reason for the data being collected was explained.

Low confidence in service staff (clinical and non clinical) to be LGBTQ+ aware and sensitive

An overarching theme of the discussion was that all participants had had some form of negative or unwanted experience with services in relation to their sexual orientation, gender or trans status, and that this contributed to a general lack of confidence and trust in services – particularly healthcare – to conduct monitoring in a sensitive and appropriate way. Within this general theme, several strands emerged:

Assumptions about sexual practices and physiology

Concerns about service staff making incorrect assumptions in relation to sexual orientation and gender identity was a key and repeated theme throughout all parts of the focus group. Indeed, a key barrier to providing monitoring information was the perception that service staff may be liable to make unwelcome assumptions about an individual's sexual practices and partners and embodiment based on the information provided. It was stated that a perceived lack of

understanding of gender diversity often fuelled incorrect assumptions about sexual orientation. Again, trans and non-binary individuals shared their experiences of particular challenges with their sexual orientation no being understood by clinicians. One participant said that, when done poorly, sexual orientation, gender and trans status monitoring…

> *"…could lead to assumptions about what kinds of relationships and what kinds of sex people are having, and the kind of healthcare they need access to. Gay sex doesn't mean the same thing for each relationship"*

Staff discomfort with LGBTQ+ issues

A perception of clinical staff as uncomfortable addressing LGBTQ+ issues or acknowledging LGBTQ+ identity also emerged throughout the discussion as a common theme. It was perceived by some that clinical staff in general, and GPs in particular, are not comfortable or interested in talking to patients about sexual orientation, gender or trans status.

"GPs don't want to discuss sexuality, they don't want to discuss anything about that […]"

The main issue in relation to comfort was not the participant's own trepidation talking about their sexual orientation, gender or trans status, but the clinicians' awkwardness creating discomfort.

> *"I think the comfort level is important, and I'm not sure how many GPs would be comfortable talking about this. […]* ***It would be more embarrassing for me to sit listening to my GP feeling awkward about it. I wouldn't feel awkward but I'd feel awkward for him feeling awkward.***"

Lack of staff awareness with LGBTQ+ issues

A perception of staff in healthcare settings as lacking LGBTQ+ awareness was a common theme throughout was the general perception that most healthcare staff and clinician had a low level of LGBTQ awareness, and that positive experiences – though certainly present – were the exception to the rule. Particular disappointment was also expressed about having experienced these issues in Brighton and Hove, which many participants agreed should exemplify higher standards of LGBTQ+ awareness due to the city's large and visible LGBTQ+ community.

Trans and non-binary patients facing unnecessary barriers to changing names and pronouns

One participant shared an experience of being told they were not able to change their name with their surgery without a gender recognition certificate. They subsequently learned that this was not true, and that the request made by the surgery of this was illegal. They changed GP surgery to one they had identified as LGBTQ+ friendly via the 'Transfigurations' website, and were able to easily have their name change recognised there.

Erasure of older people

One participant highlighted that monitoring could be a good way of addressing the prevailing issues of LGBTQ+ older people' gender and sexuality being erased in health and social care settings. She stated that, particularly in care home settings, staff were not aware of the prevalence of LGBTQ+ residents, or else tended to demonstrate a lack of acceptance of LGBTQ+ people.

"There's an attitude in care homes that doesn't accept this community'"

One participant highlighted that monitoring could be a good way of addressing the prevailing issues of LGBTQ+ older people'

Monitoring should be conducted regularly, not as a 'one-off'

Through the discussion, concerns were raised about up-to-date information not being captured. It was discussed that sexual orientation, gender identity and trans status evolve over time, and that services should therefore try to monitor on multiple occasions. It was also suggested that a centralised online platform in which individuals could access and amend their own personal details and monitoring data as and when they see fit would be useful.

It was noted that only capturing information once (usually at the point of joining a service) was particularly problematic for trans and non-binary individuals going through a period of transition, whose most up-to-date information may be missed, resulting in unpleasant instances of being mis-gendered or having the incorrect name used.

It was also noted that there was a need for regular monitoring because the information of those who initially engaged with a service prior to the service's introduction of monitoring would be missed.

One participant said she had been with her current GP surgery for 12 years and never asked about her sexual orientation in that time. She expressed a concerns that if any monitoring changes only apply to new patients, a great deal of data on existing patients will be missed.

Lack of clarity about purposes of monitoring

A second overarching theme concerned participants universal experiences of lacking clarity about why they were being asked monitoring questions – how the data would be used and why. This fed into a number of further concerns and issues that negatively impacted their comfort and confidence engaging with monitoring, as well as their valuing of the practice and process.

People may wish to provide different responses depending on the reasons monitoring questions are being asked and how the data will be used

A repeated and strong finding of the focus group was that participants may find it difficult to answer a question if they do not know why they are being asked and how the data will be used. Respondents may wish to answer a question about their sexual orientation differently, for instance, if they understand that it is being used for equality and diversity purposes to understand their identity, versus if the information is being treated as having clinical significance.

A widely shared view was that, particularly in clinical settings, patients need to know *why* they are being asked, so they know what level of detail to provide. If the information is being gathered for clinical purposes, they will want to provide different levels of information than if it is being collected for demographic monitoring only. Services must therefore be clear about - and communicate – what they need to know and why.

Without understanding the reasons for monitoring, respondents are not able to provide informed consent

Throughout the discussion, a recurring theme was that individuals were uncomfortable providing personal information about themselves without knowing why it was being asked or how it would be used. They were not sure what they were consenting to by providing the information.

Perception of monitoring as a meaningless 'box ticking' exercise

Related to the above theme was a perception of some participants that monitoring may not be being used to the benefit of patients and service users, but rather as a 'box ticking' exercise that lacked meaning.

> *"Are these questions being asked for the patient, or is it just so that the GP can tick another box? If it isn't for the person being asked, for their wellbeing, then why would they answer?"*

Information shared should be used constructively

There was a shared view in the group that if data was collected, services had a duty to use it constructively for the patient/service users' benefit, or for improving services. It was generally agreed that as long as this was assured, they would be happy to provide this information. However, experiences with providing clinically significant monitoring information which was then ignored was a common experience in the group, and fed a perception that monitoring was being used as a meaningless 'box ticking' exercise.

One participant stated that they would prefer for monitoring either to be *"completely anonymous, for them to get snapshot of the community, OR they actively use those questions on an individual level, rather than saying 'we've got all this information about you, we're going to put this information on your records, but we're not going to do anything about it. […] If they're not going to actively use that information I would prefer for it not to be recorded, but I don't mind doing something anonymously"*

Information sharing between services and departments

Participants universally agreed that they would like for monitoring information to be shared between services so that all staff they came into contact with would understand their particular identity and situation, without having to explain it each time.

> "IT'S NOT JUST THE GP, THEY'RE THE LAST PERSON WHO WILL SEE WHAT YOU DO. IT'S ALL THE OTHER PEOPLE BEFOREHAND AND AFTERWARDS […]"

Format preference

We asked participants in which formats and situations they would be comfortable sharing monitoring information, and in which they would not. The following themes emerged:

Paper forms and online options are preferred

There was general agreement throughout the group that paper an online forms were the preferred medium for sharing monitoring information, due to the privacy and autonomy these formats afford.

> "I'D DEFINITELY PREFER TO BE ASKED ON PAPER OR ONLINE THAN SOMEONE ASKING ME THOSE QUESTIONS AND WRITING THEM DOWN THEMSELVES, SO THERE'S SOME KIND OF PRIVACY AROUND IT"

It was also expressed that paper forms let the person provide answers in their own time, and that this is valued, particularly in light of the often rushed nature of clinical interactions.

> "IT'S NOT TIME LIMITED, SO YOU CAN TAKE IT FROM THE SURGERY AND THEN DROP IT BACK LATER BECAUSE I'M JUST IMAGING SOME OF THE DOCTORS I SEE MIGHT RUSH YOU, OR YOU MIGHT BE RUSHED INTO MAKING THOSE DECISIONS, OR THEY MIGHT EVEN MAKE THOSE DECISION FOR YOU"

Happy to speak with GP provided there is a good relationship

There was general agreement that individuals would be happy being asked the questions in face-to-face consultations with clinicians, but only if there was an existing, positive relationship. This attitude was largely attributed to past negative experiences discussing sexual orientation, but particularly gender and trans status, with healthcare professionals. It was also stated that, again, an understanding of why the data was being collected was important.

> *"I'd be happy for her to ask me face to face because I like her and I trust her, but first of all I'd want her to tell me why she's doing it"*

"I WILL HARDLY EVER SEE THE SAME GP IN A ROW SO I WOULDN'T BE ABLE TO BUILD UP THE KIND OF RELATIONSHIP WHERE IT WOULD BE APPROPRIATE FOR THE GP TO BRING UP THOSE QUESTIONS OR IT WOULD BE A COMFORTABLE CONVERSATION."

Telephone is not appropriate for monitoring purposes

Participants universally agreed that telephone would not be an appropriate or comfortable format for sharing monitoring information, due to the assumptions commonly made by staff about gender on this basis. This was a particularly strong feeling among trans and non binary participants, who shared their experiences of being mis-gendered on the telephone. While it was acknowledged that training could address and challenge the assumptions made by staff about gender based on voice, there was a general consensus that the telephone would be a particularly stressful medium for monitoring.

"THEY ASSUME SO MUCH FROM THE SOUND OF YOUR VOICE"

Need for sensitivity and awareness vis a vis gender and trans status

Through the discussion, several trans and non binary participants acknowledged the very high rates of stress many trans and non binary people face in navigating healthcare services, as well as everyday life in society in general, due to continued stigma of these groups. As such, it was stated that, when asking about gender and trans status, service staff and clinicians in any setting should make an effort to be respectful and straightforward. It was repeatedly stated that it was important for it to "not be made a big deal of".

Concerns about discrimination in other services

One participant said that they would be happy to share their information within their current service, which they trust, but that, due to past negative experiences in other services, would be concerned about facing discrimination if they were to access a different department, with which they were not familiar, that also had access to this information. In support of this point, another participant discussed the challenges of moving between more and less accepting surgeries, and how their experience of being accepted as trans varied greatly between these.

"I CAN GET THE IDEA OF IT KIND OF BEING NICE TO BE ASKED [...] BUT THEN IT'S ON YOUR RECORDS. AND IF YOU GET A NEW GP, OR MOVE TO A NEW PLACE [...]THEN YOU THINK, MAYBE IT WASN'T SUCH A GREAT IDEA'"

Need for independent LGBTQ+ affirmative accreditation

A repeated theme was that participants would like to know that a service is LGBTQ+ friendly before they would feel comfortable to provide monitoring information. Negative experiences with healthcare services in relation to sexual orientation, gender and trans status were prevalent in the

group and there was a shared view that services should work towards and demonstrate a certain level of LGBTQ+ competence.

> *"Some kind of indication that the surgery understands about trans and non-binary issues and is comfortable [is important].* ***If you're disclosing what could be really sensitive personal information you kind of want to know that it's not going to be used against you and that the surgery knows what you mean and they're going to be sensitive about it.*** *Knowing that they understand what it means, and if they've had training you'd feel more comfortable disclosing this kind of information if they've been through some kind of approval process"*

An other participant said they relied on websites like 'Transfigurations' and leaving reviews on google of different surgeries to find 'LGBTQ+ friendly' surgeries and GPs.

However, it was emphasised that it was non-clinical staff, as well as clinical, that would benefit from LGBTQ+ awareness training. Several participants described situations in which reception staff had responded negatively to their disclosure of their gender, sexual orientation or trans status in a way that had left them feeling embarrassed and uncomfortable.

> *"We're talking about GPs, but really the admin staff and the reception staff, they're the front line and they're the ones you'll often deal initially with"*

Another strength of external LGBTQ+ competence accreditation was that it empowered individuals to be more informed in their choice of healthcare provider. It was felt that this would go some way in overcoming some of the perceived "power dynamic" usually present between doctors and patients, and make LGBTQ+ people more aware of their rights to a good standard of care.

Issues with self-sign-in machines

Several participants noted that, even if monitoring forms were trans and non-binary inclusive, many surgeries now use self-sign-in machines which offer only 'male' and 'female' options. One trans participant said:

"[THE SELF SIGN-IN MACHINES] INVARIABLY FAIL ME. IT'S YEARS AND YEARS SINCE ALL MY NHS RECORDS HAVE BEEN ALTERED, BUT IT STILL DOESN'T WORK"

New data protection act implications

It was also raised by one participants that the new data protection act would mean that service providers will need to rethink their monitoring and data handling practices. People will need to be made more aware of their rights, particularly in terms of subject access requests. Another participant also expressed that they would like more transparency about how their data was used and stored, particularly in terms of its 'shelf life' – how long it would be stored for – and with whom it would be shared.

LGBTQ+ Community Survey

The survey for the LGBTQ community was in an online format, live over a three-week period in February and March 2018. It was promoted via the LGBT Switchboard's social media platforms and

through the HIP Newsletter, as well as via circulation through other local LGBT groups and community organisations.

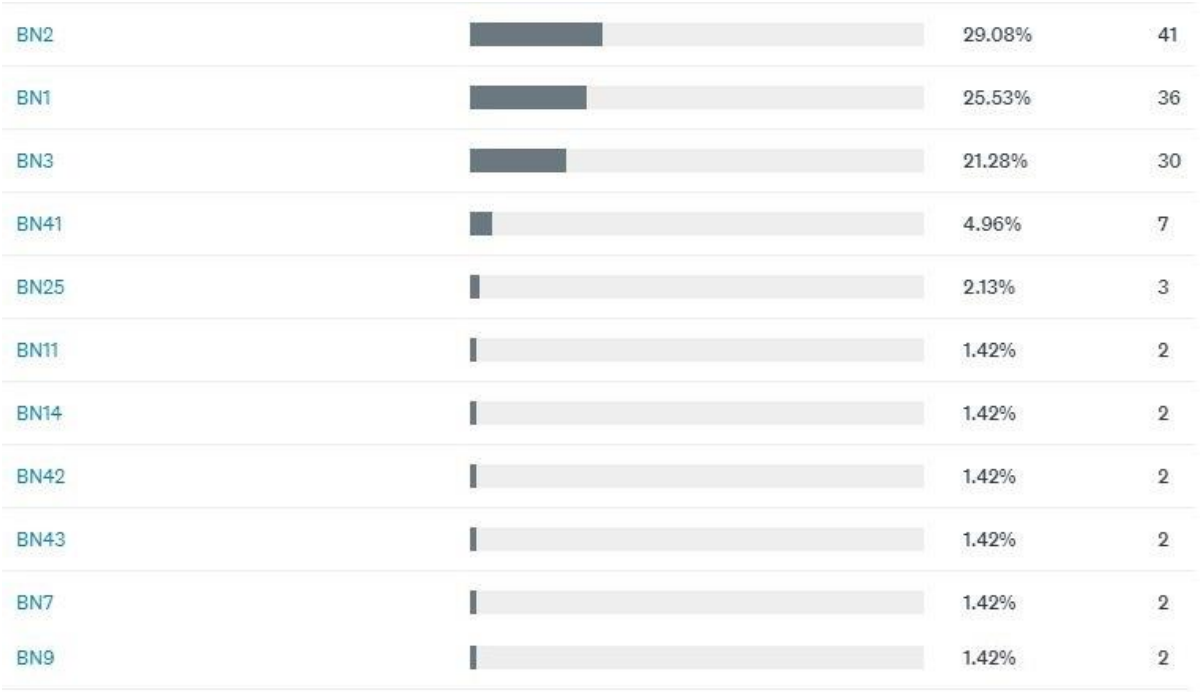
Demographics

Participants were all first presented with an initial screening question, which limited the sample, by self-exclusion of participants who did not meet certain criteria. The screening question limited the sample to *'LGBTQ+ (lesbian, gay, bisexual, transgender, queer or questioning and other sexual minority people) who live, work, study or socialise in Brighton and Hove'.* A total of 158 individuals responded and, after this question, there were a total of **154 eligible respondents**.

At the beginning of the survey, data was collected on participants' postcode area, age, sexual orientation, gender, trans status, intersex status, religion/spirituality, ethnicity and disability.

Q2: Neighbourhood: 141 answers

We asked respondents to provide the first part of their postcode. The highest prevalence of respondents were located in BN2 (29%, 41), followed by BN1 (26%, 36) and BN3 (21%, 30). Smaller numbers of respondents (2-7) were located in postcodes. 5% (7) were based in BN41, 3 (2%) respondents were located in BN25, and 2 respondents each (1%) were located in BN11, BN14, BN42, BN43, BN7 and BN9.

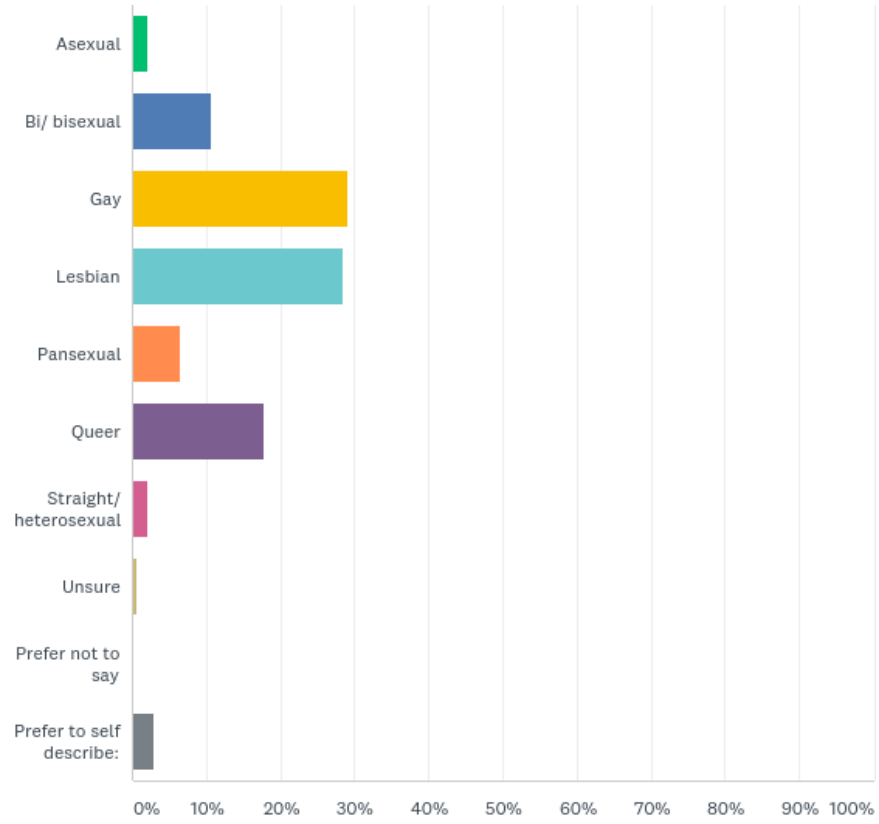


Q3: Sexual Orientation: 141 answers

We asked respondents "How would you describe your sexual orientation?" Participants were provided with a free text field to provide their preferred term under 'prefer to self-describe'.

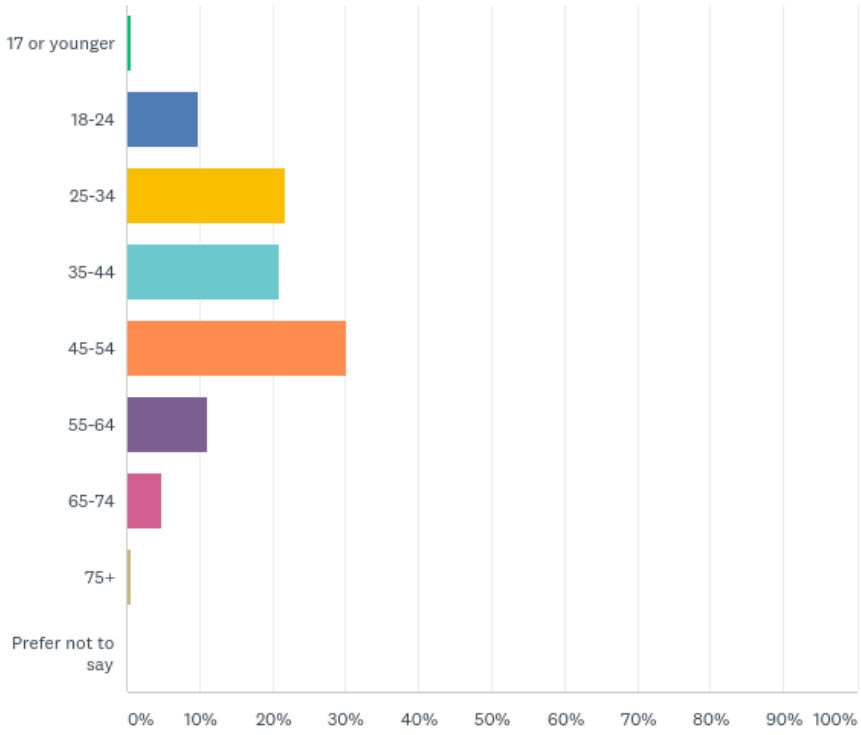
The majority of respondents identified as Gay (29%, 41) or Lesbian (40, 26%), followed by Queer (18%, 25) and Bi/bisexual (11%, 15). 6% (9) identified as Pansexual, 3 as Asexual (2%) and 3 as Straight/Heterosexual. 1 respondent chose 'unsure' and 4 chose to self-describe, and offered the following:

- *Straight (a dude who is MtF fluid, into cis females)*
- *Gay & queer*
- *Bi Asexual*
- *Do not define or label my sexuality in any way*



Q4: Age: 143 answers

We asked respondents : 'What was your age at your last birthday?' The largest proportion of those responding were aged 45-54 (30%, 43), followed by 35-44 (21%, 30), and 25-34 (22%, 31). 11% (16) were aged 55-64 and 10% (14) were aged 18-24. One participant each was aged 17 or younger and 75+ respectively (<1% each).

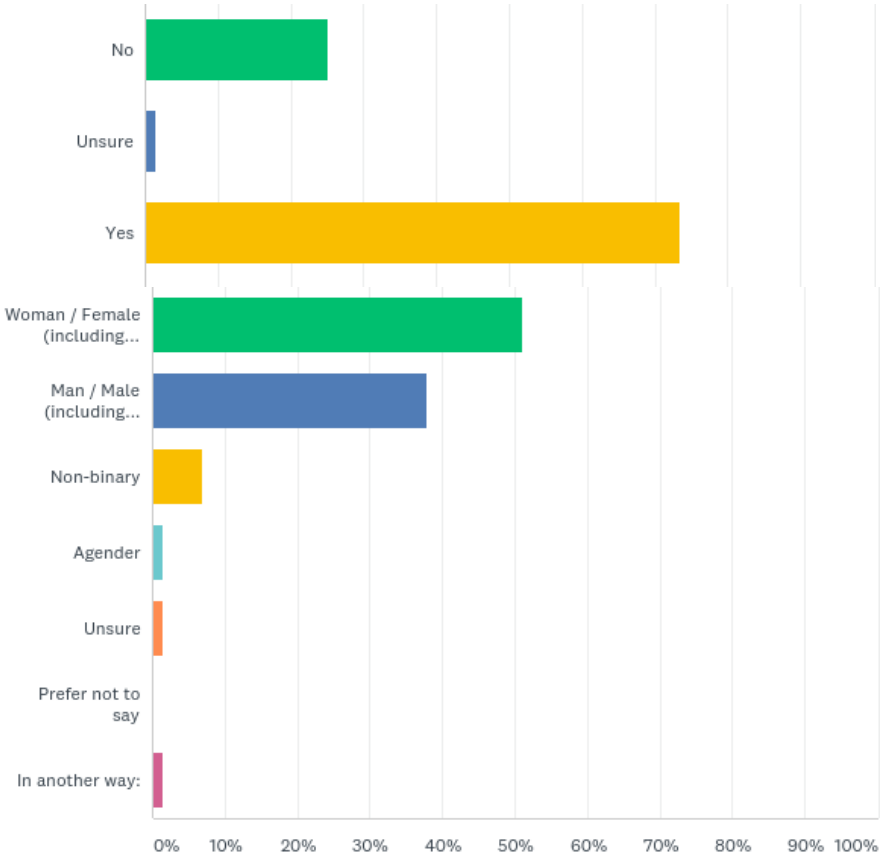


Q5: Trans Status: 143 answers

We asked "Is your gender the same as the gender you were assigned at birth?" The majority of respondents selected 'yes', identifying themselves as cis-gender, at 73% (105). 25% (36) answered 'no. 1% (2) chose Unsure.

Q6: Gender: 143 answers

We asked respondents "How would you describe your gender?" We offered the options 'female/ woman (including trans woman)', 'male/ man (including trans man)', 'non-binary', 'agender', 'unsure', 'prefer not to say', and 'in another way', with a free text field in which to self-describe.

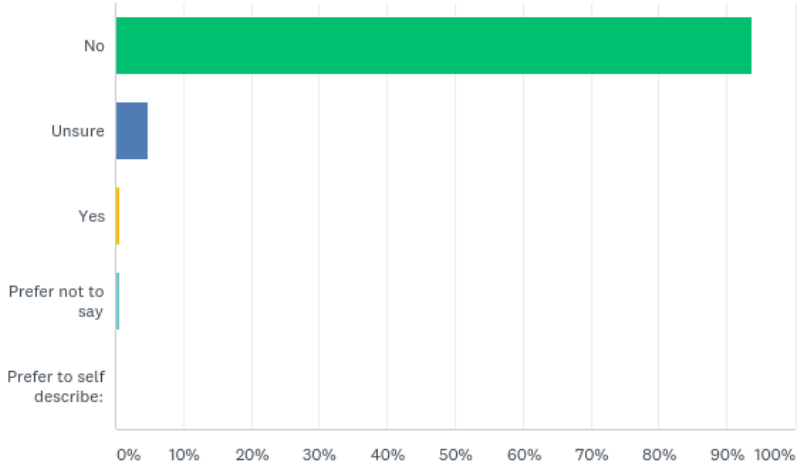


51% (73) said 'female/ woman (including trans woman)', and 38% (54) said 'male/ man (including trans man)'. 7% (10) said 'non-binary', 1% (2) said 'agender', and 1% (2) said 'unsure'. 2 (1%) said they identified in another way and provided:

- *Trans masculine or just trans*
- *Genderfluid (my current belief)*

Q7: Intersex Status: 143 answers

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." The majority of respondents selected 'no' (94%, 134). One selected 'yes' (1%). 5% (7) were unsure, and 1 (1%) preferred not to say.



Q8: Disability: 142 answers

We asked respondents "Do you live with a health condition, impairment, learning difference, or neurodivergence that shapes your day to day activities?"

Nearly half of respondents (41%, 56) identified as having a mental health difficulty. 36% (54) said they had no known health condition, impairment, learning difference or neurodivergence. 25% (36) had a long-term illness or health condition. 19% (27) had some form of neurodivergence, and 8% (12) had a specific learning difficulty. 8% (11) stated they had a physical impairment or mobility issue and a further 8% (11) identified themselves as having a social or communication condition.5% (7) were D/deaf or had a hearing impairment, and three respondents chose to self-describe:

ANSWER CHOICES	RESPONSES	
No known health condition, impairment, learning difference, or neurodivergence	38.03%	54
Long-term illness or health condition (e.g. cancer, chronic heart disease, diabetes, epilepsy, HIV)	25.35%	36
Mental health difficulty (e.g. addiction, anxiety, depression, eating disorders)	40.85%	58
Physical impairment or mobility issues (e.g. difficulty using your arms, using a wheelchair)	7.75%	11
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)	19.01%	27
Social or communication condition (e.g. a speech and language impairment, Asperger's syndrome/ other autistic spectrum condition)	7.75%	11
Specific learning difficulty (SpLD) (e.g. AD(H)D, dyscalculia, dyslexia, dyspraxia)	8.45%	12
Blind or visual impairment that can't be fixed with glasses	0.00%	0
D/deaf or a hearing impairment	4.93%	7
Prefer not to say	0.00%	0
Prefer to self-describe:	2.11%	3
Total Respondents: 142		

- *PTSD Survivor of Same Sex Domestic Abuse now out of Refuge*
- *Bipolar affective disorder*
- *Rare & Orphan Diseases*

Q9: Religion, faith and spirituality: 143 answers

We asked respondents "If you have a religion, faith, or spirituality, how would you describe it?"

38% (55) respondents chose No Religion, and 26% (37) chose Atheist. 10% (15) identified as Christian, and a further 8% (12) as Spiritual. 4% (6) were Buddhist, 1% were Jewish (1) and 1% (1) were Muslim. 2 (1%) selected Prefer Not to Say.

We found a relatively high rate of self-description response for this category, with 10% (14) of respondents choosing to provide a different response than listed:

- Pagan (4)
    - *2 said "Pagan", 1 said "Agnostic with Pagan leanings", 1 said "secular Pagan"*
- Agnostic (5)
    - *4 said "agnostic", 1 said "Agnostic with Pagan leanings"*
- Spirtual/ atheist/ quaker (1)

- Witch (1)
- Wiccan (1)
- Humanist (1)
- Roman Catholic (1)
- Quaker (1)

Q10: Ethnic Origin: 143 Answers

We asked respondents: "How would you describe your ethnic origin?"

8% (11) of respondents were from a Black, Asian or Minority Ethnic (BAME) background. The majority of respondents identified themselves as white British, at 71% (101). 7% (10) were white European. 4% (6) self-identified as White: Irish and 9% (13) as being from an other white background. 1% (2) respondents were Black/ Black British Caribbean, and a further 1% (2) were of Mixed Asian descent. 3% (4) were from an other mixed background. 1% (1) respondent identified as Mixed: White and Asian. 4 (3%) chose to self describe, stating:

- *Jewish*
- *Arab Irish*
- *Mixed British Irish Indian*
- *Don't know*

Monitoring Question and Answer Option Preferences

Sexual Orientation Monitoring

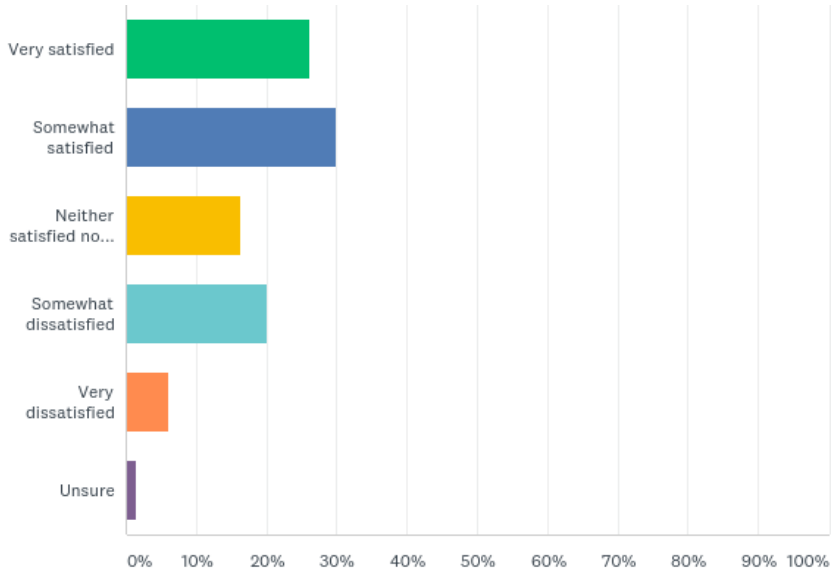
In this part of the survey, we asked respondents about their views on the ways they would like to be asked about their sexual orientation, using the NHS Sexual Orientation Monitoring Information Standard criteria and recommendations from the accompanying Good Practice Guide as a starting point.

Views on the SOM Information Standard

We presented respondents with the options listed by the NHS Sexual Orientation Monitoring Information Standard, asked about their level of satisfaction with these, and invited comments.

The options offered by the Standard, as they might appear on a self-completion monitoring form, are:

"Heterosexual or Straight", "Gay or Lesbian", "Bisexual", "Other sexual orientation not listed", "Unsure", and "Prefer not to say".



- The overall level of acceptance of the terms offered by the NHS' Information Standard was reasonably high, with more than half (56%) of respondents saying that they were either

"very satisfied" (26%) or "somewhat satisfied" (30%) with the options offered.

- However, more than one in four (26%) were either "somewhat dissatisfied" (20%) or "very unsatisfied" (6%)
- 16% were "neither satisfied or unsatisfied" and 1% were "unsure"

Comments

There was a strong comment response to this question, with 88 individual responses. These clustered around a set of key themes:

Additional guidance (2% of comments)

Two comments suggested that additional guidance should be provided when monitoring questions are being asked, to clarify the meaning of options or explain the reasons for monitoring.

Broad or vague (7% of comments)

Six commenters expressed a view that the current options provided were felt to be too "broad" or "vague" in nature.

Dislike term or option (11%)

Ten commenters expressed dislike for a currently named option. These included those with aversion to the terms 'lesbian' and 'bisexual', and a desire for different terminology options to be available. A dislike of the 'other' option was also expressed.

"I don't like the 'other' option - seems to lump a lot of different types of sexualities together"

A commenter also pointed out that 'unsure' could be interpreted in different ways.

"[I prefer] 'Questioning' rather than 'unsure', as the latter implies the person might not have understood the question."

Non-inclusive (9% comments)

Eight commenters said the current options were non-inclusive, particularly of trans and non-binary individuals, due to the binary-gender oriented terminology of the named available options.

"I used to identify as gay so it was easy. Now I am trans male and don't know what to tick! I still go out with women but don't identify at all with "straight". For me I guess now I've transitioned, queer would be a good option for my sexuality."

"How will they see trends in issues for people of 'other sexual orientation'? It's not as black and white as gay straight or bisexual. This erases people who fall into other categories"

Format presentation (alphabetisation) (2%)

Two commenters said they would prefer for the options to be presented alphabetically.

Further named options (39% of comments)

The proportionally largest comment theme was the preference for further named options to be listed. Among these Queer was the most common request (17% of all commenters requested this), followed by Asexual (10%). Pansexual was also recommended by several commenters. Other comments expressed dissatisfaction with the scope of available options, and made a general request for more named category options to be provided.

"Orientations such as asexual, pansexual and queer are now quite widely recognised (in the LGBTQ+ community at least) so I can't see any reason why people with these identities would be expected to tick "other" […] Who really wants to tick "other" about an important aspect of their identity?"

Label averse (1% of comments)

One commenter expressed a preference not to label their sexual identity. If a self-describe option were available, this may have been the most suitable option to capture this information.

Monitoring averse (6% of comments)

Five commenters in total made reference to opposing the collection of sexual orientation data for monitoring purposes. In several cases, this seemed to be partially attributable to a lack of clarity about the reasons for monitoring.

Satisfied (5%)

Four commenters expressed satisfaction or acceptance of the current options.

"Our tick box descriptions are behind the curve in how (esp.) younger people are preferring to describe themselves (pan, 'just me' etc.), and the range of sexual orientations. But there's inevitably a time lag, and it feels very positive that sexual orientation is now being monitored."

Self-describe option (13% comments)

11 comments made direct reference to a preference for a free-text field 'self-describe' option.

Separate gay and lesbian (6% of comments)

These comments expressed concerns about "gay and lesbian" being included together, and a preference for two separate options to be provided for each

"I think it would be better to have gay man and lesbian / gay women as two separate options for some recording purposes, as for many things these two groups will have different views/needs/etc. and as such it's not as useful to group them together."

Wording the question

We asked respondents "How would you like a multiple-choice question about sexual orientation to be worded?" and asked them to rank the following options in order of preference, with further space to comment below. The options provided were:

- "How would you describe your sexual orientation?"
- "What is your sexual orientation?"
- "Sexual Orientation: Which of the following best describes how you think of yourself?"

"How would you describe your sexual orientation?" was the most popular question wording option

The most popular option was "How would you describe your sexual orientation?", as the first choice for around 6/10 (58%) respondents. It was also the least popular 'last choice' option, at only 5%.

"Sexual Orientation: Which of the following best describes how you think of yourself?" was selected by nearly a third (30%) of respondents, and was the second most popular first-choice option. However, it was also a relatively prevalent 'last choice' option, at 35%.

"What is your sexual orientation?" was the least popular first-choice option, with 14% of the vote. 59% of respondents gave this as their least favourite option.

	1	2	3	TOTAL	SCORE
"How would you describe your sexual orientation?" [Followed by a multiple-choice list of sexual orientations]	57.94% 73	37.30% 47	4.76% 6	126	2.53
"What is your sexual orientation?" [Followed by a multiple-choice list of sexual orientations]	13.93% 17	27.05% 33	59.02% 72	122	1.55
"Sexual Orientation: Which of the following best describes how you think of yourself?" [Followed by a multiple-choice list of sexual orientations]	30.40% 38	34.40% 43	35.20% 44	125	1.95

Comments

35 individuals left comments. Throughout these, several key themes emerged as important considerations in the design of a sexual orientation question:

Self-description

Many commenters made reference to self-description being important. It was also noted that this allowed for the sometimes fluid and changing nature of sexual orientation, which questions that imply a fixed state (e.g. "What is your sexual orientation?").

"It's very hard to be absolute in an answer ... I sometimes describe my self as gay, occasionally as lesbian, and in the past I would have said bisexual even though I was in a heterosexual relationship […] We need to find a way of representing this fluidity, or trying to capture a sense that this is only current identity which is open to change."

Acknowledgement of limitations of the question

Some commenters said they valued a wording that acknowledged the options would be inevitably limited and invited a 'best fit' response.

"Better with the acknowledgement of the limited choices ie "if you had to choose from the following""

Accessibility and clarity

A common theme was also that the question should be clear, straightforward and jargon-free. It was also pointed out that the question and any accompanying written or verbal guidance should be in a clear and concise format with accessibility criteria in mind.

"It's a very personal question that doesn't really bother me if I'm asked face to face but on a form people need to use clear concise easy to understand language and punctuation not confused readers especially those with autistic spectrum conditions and learning disabilities it needs to be accessible to all"

The reasons for asking must be explained

In addition to the wording of the question itself, several commenters noted the need for the reason for asking the question to be explained alongside. This was a running theme throughout the focus group and survey, as the reasons for monitoring will influence the response someone chooses to give.

"It's difficult to give suggestions when I don't know why you're asking the questions. ***You need to decide if you're wanting to know about sexual identities, sexual orientations, or sexual practices, and that has to be reflected in the questions."***

Alternative question wording options offered included:

- *"How would you like your sexual orientation to be described, if you are unhappy with the choices or they do not fit how you feel please tell us in the space provided."*
- *"Which of the following options best describes your sexual orientation / sexuality?"*

Gender Monitoring: Questions and Answer Options

In this part of the survey, we asked respondents about the question and answer options they would like to be offered when being asked about their gender for monitoring purposes.

Wording of the Gender Question

We asked respondents "How would you like a multiple choice question about gender to be worded?" and asked them to rank the following options in order of preference, and provided space to comment further below.

	1	2	3	4	5	TOTAL	SCORE
"How would you describe your gender?"	31.09% 37	21.01% 25	28.57% 34	17.65% 21	1.68% 2	119	3.62
"How would you describe your gender identity?"	24.58% 29	40.68% 48	22.03% 26	8.47% 10	4.24% 5	118	3.73
"What is your gender?"	8.47% 10	11.02% 13	9.32% 11	21.19% 25	50.00% 59	118	2.07
"What is your gender identity?"	9.32% 11	11.02% 13	23.73% 28	44.07% 52	11.86% 14	118	2.62
"Gender: Which of the following best describes how you think of yourself?"	31.36% 37	16.95% 20	15.25% 18	6.78% 8	29.66% 35	118	3.14

We offered five options:

- "How would you describe your gender?"
- "How would you describe your gender identity?"
- "What is your gender?"
- "What is your gender identity?"
- "Gender: Which of the following best described how you think of yourself?"

"How would you describe your gender?" was the most popular first choice option (31%). However, it had the second highest score overall, at 3.62.

"How would you describe your gender?" or "How would you describe your gender identity?" were the most popular wording options for a gender monitoring question

"How would you describe your gender identity?" was the second most popular first choice (25%). However, it had the highest score overall, at 3.73.

While the "How would you describe…?" wording (56% in total) was a clear preference, the preference for "gender" rather than "gender identity" in this wording was notable, and reflected in many comments, as explored below.

"**Gender: Which of the following best describes how you think of yourself?"** (31%)

This was the second most prevalent first-choice option. However, several comments noted an aversion to the wording as patronising, implying that others do not recognise one's gender, or

indicating an overly specific kind of relationship to one's gender that does not reflect some people's experience.

"Including 'how you see yourself' implies it isn't recognised by others."

"I don't necessarily 'think of myself' as a woman, I just am one."

"What is your gender identity?" (9%) / "What is your gender?" (8%)

While this wording was the overall least popular first-choice option, an interested indication of a slight preference with regard to use of "gender" versus "gender identity" was related, with 1% more respondents preferring the latter as a first choice, and earning an overall score of 2.62, in contrast to 2.02 for "gender" alone. 50% of respondents chose "What is your gender?" as their least favourite response.

One commenter noted that the wording of this question may be overly-direct and felt "a little aggressive".

Comments

Comments revealed similar themes to those on the wording of the Sexual Orientation wording question:

Language of "identification" and use of the term "identity"

Commenters noted that use of the word "identity" in relation to gender can be experienced as patronising, minimising or confusing.

"'Gender identity' sounds like you don't believe my gender is real"

"I don't like being asked how I describe my gender identity because I don't identify with the expectations of my gender."

"Using the words gender and identity in same sentence is confusing I would need a key to explain the differences it would confuse me with my autism I would need something clearer"

One commenter also noted the distinction between 'defining' and 'identification', and that this is a difference that requires some consideration in question design. It was also indicated that an explanatory component of the question could be valuable:

> Use of the term 'identity' as in 'gender identity' can be perceived as invalidating:
> *"Gender 'Identity' sounds like you don't believe my gender is real"*

"How people identify/describe their gender, and whether their gender is as assigned at birth, are often conflated, but are different (eg. don't 'identify' as trans). Teasing out differences makes sense to some, but it utterly confusing for others. A difficult tightrope. Is there an opportunity in asking the question to provide some gentle education?"

Acknowledgement of limitations of the question

Again, some commenters said they valued a wording that acknowledged the options would be inevitably limited and invited a 'best fit' response.

"'How would you BEST describe....' The word 'best' being added recognises it is not finite"

The reasons for asking must be explained

As with the question for Sexual Orientation, it was emphasised again that, in addition to the wording of the question itself, there was a need for the reason for asking the question to be explained alongside. This was a running theme throughout the focus group and survey, as the reasons for monitoring will influence the response someone chooses to give.

A lack of explanation also possibly contributed to some commenters perception that the questions were simply a 'politically correct' 'box-ticking' exercise. Comments included:

"It's important to explain to participants what exactly you are looking for; gender identity, gender assigned at birth, etc."

"Is gender relevant in the circumstance??"

"Why is this even important? It's all becoming […] too PC"

Alternative question wording options offered included:

"Which of the following options best describes your gender / gender identity?"

Gender: Answer Options

While not everyone's gender who identifies as a man or woman, male or female is binary, for purposes of clarity in this report, the answer options here have been separated into 'binary gender' (i.e. male/female; man/woman) and 'beyond the binary', referring to terms describing genders other than these (e.g. non-binary, genderqueer, genderfluid, agender).

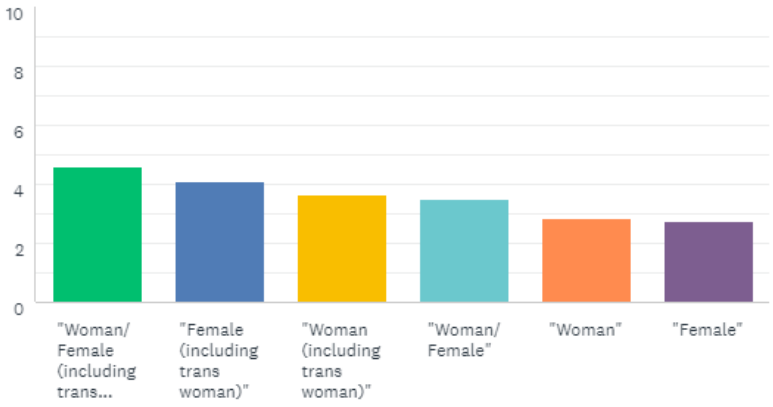
Binary Gender Options

We asked respondents to share their preferences about a range of different answer options for a monitoring question about gender. We offered five options, based on different combinations of gender- and sex-based language and inclusion/non-inclusion of an explicitly trans inclusive statement.

We asked that only those who self-identify with the following genders responded to the corresponding questions for those gender identities.

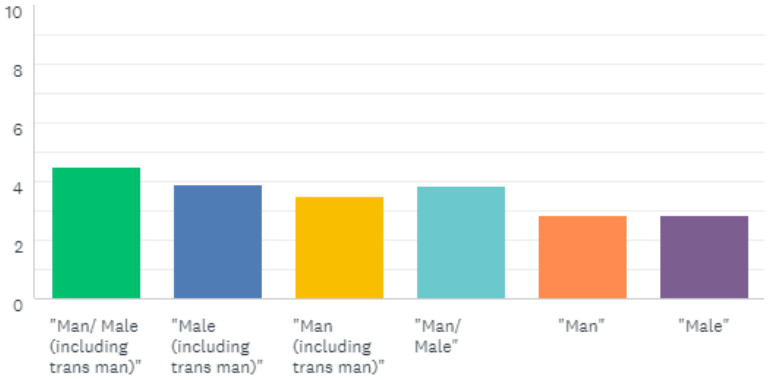
<u>Options for those who self-identify as women/ female</u>

- "Woman/ Female (including trans woman)"
- "Female (including trans woman)"
- "Woman (including trans woman)"
- "Woman/ Female"
- "Woman"
- "Female"



Options for those who self-identify as men/ male

- "Man/ Male (including trans man)"
- "Male (including trans man)"
- "Man (including trans man)"
- "Man/ Male"
- "Man"
- "Male"



- **'Sex' and 'gender' terms plus an explicitly trans inclusive statement was the most popular option for the binary gender options**
    - "Woman/ Female (including trans woman)" (44%) and "Man/ Male (including trans man) (50%) were the most popular options
- 22% said "Female (including trans woman)" and 13% said "Male (including trans man)"
- 6% said "Woman (including trans woman)" and 9% said "Man (including trans man)"
- 'Sex' and 'gender' terms together were the second 14% "woman/ female" and 18% said "Man/ Male"
- 13% said "woman" and 6% said "man"
- "Female" was a less popular option, with only 10% of the vote; 16% said "male"

72% said they would prefer a gender option that was explicitly trans-inclusive by adding "Including trans woman" or "including trans man"

Overall, 72% of self-identified LGBTQ men and women said they would prefer an option that was explicitly trans-inclusive by adding "Including trans woman" or "including trans man".

The different between self-identified men and women in relation to preference of sex versus gender wording is of note here. Women had a stronger aversion to sex-based language ("Female") than men did with "male". A stronger overall trend of preference was discernible among women than men.

Comments

The comments extended the quatitative data on preferred binary gender options, with several key themes emerging:

An explicitly trans-inclusive statement as valued

Supporting the above finding that 72% of respondents chose a gender option with an explicitly trans-inclusive statement, several comments stated that an explicitly trans inclusive statement was welcome and helpful. It was felt that it would help to 'normalise' the term, and that a failure to include this could contribute to further exclusion of trans people.

"Whatever option is chosen you need to include the term 'trans' because otherwise it excludes people and may lead to further isolation"

"I like the trans option being next to the word. Helps to normalise the term."

It was also suggested that 'including trans man'/ 'including trans woman' could be extended to additionally include the terms transmasculine and transfeminine, as distinct from the former.

An explicitly trans-inclusive statement as problematic

However, several commenters also drew attention to the possibility of an explicitly trans inclusive statement being problematic, due to highlighting difference in a way that was felt to privilege cisgender people, or could make trans respondents feel uncomfortably 'othered'.

"I think that putting including trans man implies that trans men might not be included. It's a tautology. It's like saying are you a human (including disabled people). To me it highlights difference. Couldn't GP's find other ways to indicate they are trans inclusive on monitoring materials?"

"Trans women should not be made to feel like they need to be especially mentioned"

"I am a little torn about this- I think in a way it is good to say "including trans woman", but in another way it might be quite othering- the terms female or woman should always include trans woman."

Sex-based terms as problematic

Several respondents commented about sex-based terminology (i.e. male/female) being problematic, 'old-fashioned' and as having derogatory associations. It was also discussed how this could be potentially exclusive for trans people, with gender-based terms such as man and woman being favoured.

"Female is so hard to feel entitled to claim... it feels like it really refers to a specific physiology, and internal parts I've never had, a reproductive ability I've never had. Woman is easier for me."

"People usually only use 'female' to talk about old fashioned views about biology and ideas of two sexes. Or in a derogatory way (like "females are bad at parking") - sexist people often use the word."

Institutional confusion over sex and gender

Some comments pointed out the prevailing confusion regarding the distinction in meanings between sex and gender, and that a question must therefore be clear about which is being requested. However, as discussed above, even where 'sex' is directly requested, precisely what is being asked is not always clear, and can be particularly problematic and non-inclusive for trans and/or non-binary people

"If this is the question about gender then it needs to use the word woman rather than female, otherwise it's confusing as it looks like you're asking about biological sex rather than gender."

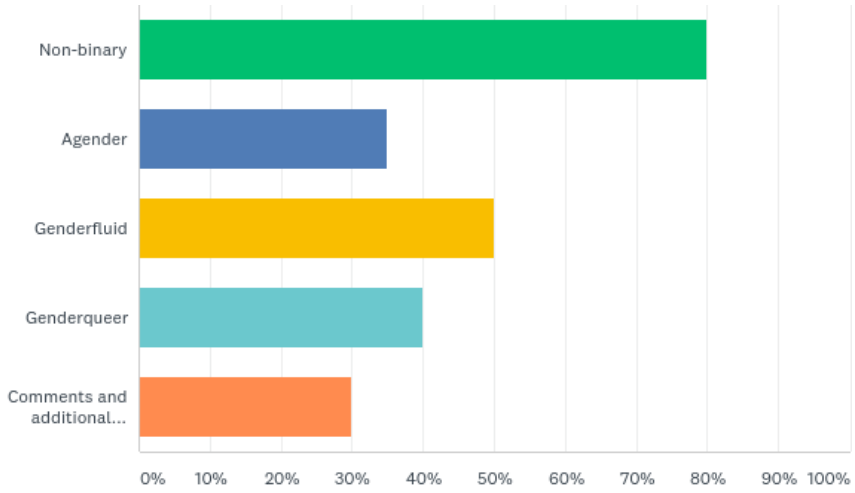
"Say 'women' not 'female' as many people believe 'female' is just about biology"

Beyond the binary Gender Options

All respondents in this section self-identified as being of a gender other than the binary man/male and female/ woman options as explored above.

We asked which other-than-binary gender options they would like to be offered in monitoring materials.

- 80% of respondents said “Non-binary” should be an option
- 50% said “Gender fluid” should be an option
- 40% said “Genderqueer” should be an option
- 35% said “Agender” should be an option



Comments

Six respondents provided comments, which clustered around two key themes:

In favour of offering “non-binary” to encompass a range of non-binary genders (genderqueer, gender fluid, etc.)

“There are so many different labels that we use, generally just "nonbinary" will suffice as an umbrella term... but more options does feel more inclusive/welcoming”

In favour of Agender as a separate category from non-binary

“Agender/ gender neutral is different from non-binary, however, otherwise it just become another ‘other’ option”

“Include an Unsure!! Many people don’t know their gender identity”

Trans Status Monitoring: Questions and Answer Options

Response to this section was limited to those whose gender is not the same as the gender they were assigned at birth.

While this will include a high proportion of people who identity as trans and/or non-binary, it is important to acknowledge that not everyone with a trans history may identify as trans or as having a form of ‘trans status’.

Trans Status Question wording

We asked “How would you prefer to be asked on a monitoring form about whether you identify as transgender?” and asked respondents to rank four options in order of preference.

- "Do you identify with the gender you were assigned at birth?"
- "Do you identify with the gender and/or sex you were assigned at birth?"
- "Is your current gender the same as the gender you were assigned at birth?"
- "Do you identify as trans or have a trans history?"

"Do you identify with the gender you were assigned at birth?" *was the most popular wording for a trans status monitoring question*

	1	2	3	4	TOTAL	SCORE
"Do you identify with the gender you were assigned at birth?"	44.12% 15	29.41% 10	23.53% 8	2.94% 1	34	3.15
"Do you identify with the gender and/or sex you were assigned at birth?"	14.29% 5	40.00% 14	20.00% 7	25.71% 9	35	2.43
"Is your current gender the same as the gender you were assigned at birth?"	20.00% 7	14.29% 5	42.86% 15	22.86% 8	35	2.31
"Do you identify as trans or have a trans history?"	27.78% 10	13.89% 5	11.11% 4	47.22% 17	36	2.22

1st place: "Do you identify with the gender you were assigned at birth?"

44% selected this option as their first choice, and I received the highest overall score, of 3.15

2nd place: "Do you identify with the gender and/or sex you were assigned at birth?"

14% selected this option as their first choice, and 40% as their second choice, with an overall score of 2.43.

3rd place: "Is your current gender the same as the gender you were assigned at birth?"

20% of respondents chose this option as their first choice, but higher rankings in 'runner up' positions meant this option ranked third overall, with a score of 2.31.

4th place: "Do you identify as trans or have a trans history?"

Although more respondents chose this as their first choice than the 3rd place option, at 28%, this option had the lowest overall score at 2.22.

"Sometimes I don't like to think about my trans history but instead to acknowledge my gender is different to mine assigned at birth."

Comments

Comments were also provided, and raised the following key points:

Question should be description- rather than status-oriented

Several comments drew out the distinction between wordings that acknowledge the nuance and non-static nature of gender and transness, and favoured a question that provided a description of one's relationship to gender rather than asking about a specific identity. Several commenters said their gender did not match their gender assigned at birth but that they did not identify as 'trans'.

"Transgenderism is complex and full of nuance. It is also a journey for most, so not static. This should be represented in any survey questions."

"Asking outright if someone is trans or has a trans history can be challenging – asking about gender is more descriptive and accurate"

One respondent said they would like a question specifically about transition-related surgery

"An optional question should be included. Have you had, or do you plan to have, gender reassignment surgery?"

Trans Status Answer options

We asked "In addition to "yes" and "no", which additional options - if any - would you like to be offered?"

- 78% said it was important to be able to state "prefer not to say"
- 58% said they would like to see "prefer to self-identify"
- 58% said they would like an "unsure" option
- 52% said they would like "partially" to be an option

One commenter noted a preference for "other" or "other (please state)" as an option rather than "prefer to self-identify", although no reason was provided.

Another commenter noted the possibility of 'prefer not to say' being potentially 'othering':

> *"While prefer not to say is likely needed, it can't be used as a way to 'other' people, and it's not enough by itself, we need categories that cover the bases as much as is possible."*

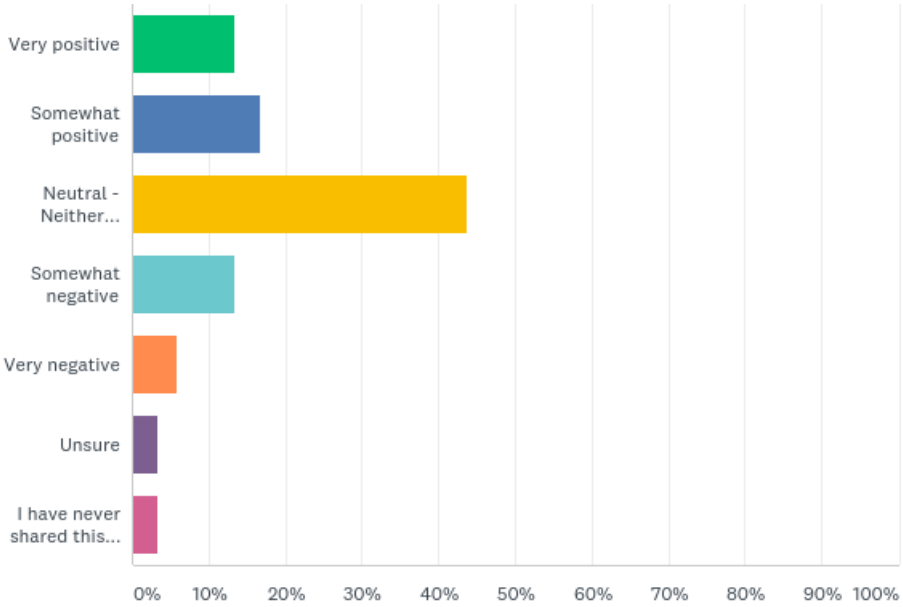
Monitoring attitudes, experiences and preferences

These questions aimed to elicit LGBTQ+ people's attitudes, experiences and preferences in relation to monitoring, in order to help understand which factors are important in influencing people levels of comfort and confidence sharing monitoring data.

Community past experiences with monitoring

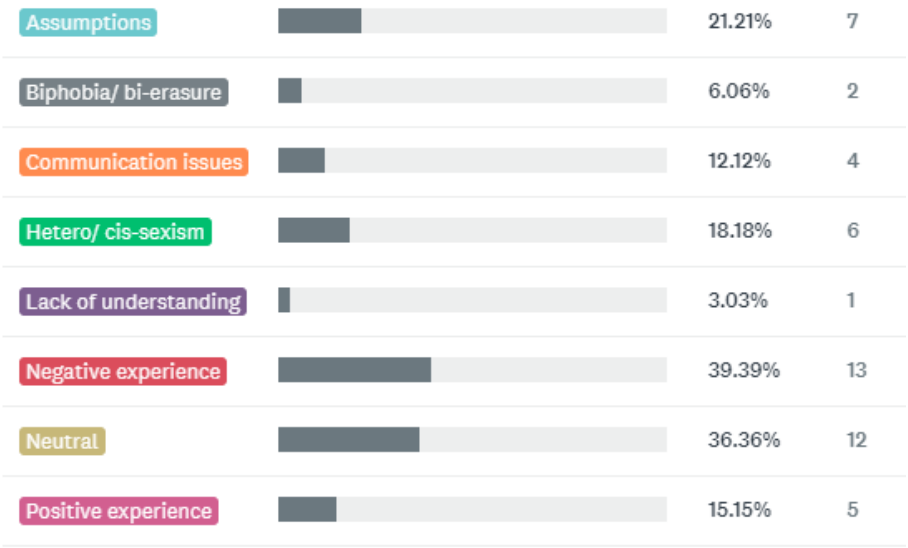
We asked respondents how comfortable they felt sharing monitoring information about their sexual orientation, gender or trans status with a healthcare or council service on the last occasion they did so.

- The largest proportion of respondents, just over one in four (43%) said their past experience of sharing monitoring information about their sexual orientation, gender or trans status was "Neutral – Neither positive or negative"
- 30% said the experience was either "very" (13%) or "somewhat" (17%) positive
- 19% said the experience was either "very" (6%) or "somewhat" (13%) negative



Comments

33 respondents provided further comments. Of those that were substantive, experiences shared clustered around the following themes:



Assumptions

More than 1 in 5 comments made reference to a negative experience of assumptions being made about their sexual orientation. These included incidences of heterosexism and bi-erasure, explored further below.

Two respondents shared negative experiences of unwelcome assumptions being made by staff about their sexual orientation.

Bi-phobia/ bi-erasure

One comment made references to instances in which bisexuality was either not included as an option in a monitoring situation, and another to a situation in which they were referred to as 'straight' and 'gay' despite saying they were bisexual.

"I've had experiences where people have referred to me as gay or assumed I'm straight, despite the fact that I stated I am bisexual."

Heterosexism and cissexism

This refers to the assumption that everyone is straight (heterosexism) or cisgender (cissexism) until established otherwise. This was a common theme, with nearly two in ten comments making reference to this form of assumption-making in monitoring situations.

"I am 'femme' and have a child, healthcare professionals always assume that I'm heterosexual and I have to correct them. There is nearly always the assumption that someone is straight until they say otherwise"

Communication Issues

More than one in ten comments made reference to negative experiences in which poor communication on the part of service providers played a part.

Lack of understanding

One comment stated a perception of service staff as lacking understanding of gender and sexual diversity.

Negative experiences

Nearly four in ten comments provided included experiences of an actively negative nature, and made reference to an unwanted, uncomfortable or otherwise difficult situation or interaction in relation to monitoring. Some of these also made reference to actively positive and neutral situations and experiences.

Positive experiences

15% of responses contained report of experiences and interactions of an actively positive nature. Some of these also made reference to experience that were neutral or also actively negative. Of these, several made reference to feeling 'supported', or treated with understanding and discretion. Being signposted to local LGBTQ+ services also contributed to making an experience feel positive.

"Always treated with the utmost understanding and discretion. I had a minor bladder operation this week and the fact that I have had reassignment surgery was not even mentioned by the consultant or any of the hospital nurses and staff."

Another respondent described *"a positive experience with a council service (supportive housing adviser at Brighton & City Council who provided me with information on local lgbtq+ services)"*

Neutral experiences

36% of comments described a situation in a neutral manner. Many of these included scenarios where monitoring information had been shared and nothing particularly positive or negative was experienced as a result. However, it is of note that many of these 'neutral' experiences may be regarded as positive due to the expectation or fear of a negative experience.

"Sexuality was not assumed to be 'straight' and there was no reaction to being told I'm gay"

"I think it was met with zero judgement, and it didn't feel like it impacted on my overall care. However I recognise that my particular gender/sexuality status isn't complicated by other aspects of my identity which means I have greater levels of privilege inhabiting these spaces (being a white cis-gendered man)"

"When the person ask me about my sexual orientation they stumbled and seemed to find it hard to ask […] Instead of saying the question they kept pausing, which prompted me to just come out with the answer... I am gay.

It wasn't a problem for me, apart from the awkwardness, but it seemed to be a huge problem for them.

There still seems to be a huge taboo around sexual orientation and gender identity and some people seem to find it hard to ask the questions, which doesn't make it any easier for us when answering"

Community barriers to monitoring

We also asked respondents about the concerns they have had or barriers, if any, they have faced to sharing information about their sexual orientation, gender identity and/or trans status with services. We provided a range of options, as provided below:

ANSWER CHOICES	RESPONSES	
Fear or past experience of discrimination from staff based on your sexual orientation	46.67%	56
Fear or past experience of discrimination from staff based on your gender	21.67%	26
Fear or past experience of discrimination from staff based on being transgender	14.17%	17
Fear or past experience of discrimination from staff based on being intersex	9.83%	11
(incorrect or otherwise) being made about n the information you provide	57.50%	69
(incorrect or otherwise) being made about ation you provide	30.83%	37
ty of the information you provide - e.g. who within information will be shared between services, or duty of care to you (such as parents, carers,	36.67%	44
ation would be used by the service	31.67%	38
Lack of trust in staff and/or the service as a whole to treat the information provided sensitively and respectfully	36.67%	44
Lack of consistent relationship with staff/ service	32.50%	39
Not understanding why the service is asking, so not sure what level of detail to share	25.00%	30
Lack of opportunity to update service on sexual orientation, gender and/or trans status when this has changed	14.17%	17
I haven't had any of these concerns	15.00%	18
Another issue(s) not listed (please comment)	5.00%	6
Total Respondents: 120		

Lack of trust in staff and services to be LGBTQ+ aware was a key barrier to monitoring *for 1 in 3 LGBTQ+ people*

***6/10 LGBTQ+ people** said concerns about **assumptions being made by staff about their sexual practices** was a significant barrier to providing monitoring information about their sexual orientation, gender and trans status*

The most prevalent barrier **was assumptions being made about people's sexual practices** based on the information provided, with nearly 6 in 10 respondents stating this as a concern.

Nearly half **cited fear or past experiences of discrimination from staff based on sexual orientation** as a key barrier to feeling comfortable providing monitoring information.

More than a third said **lack of trust in staff and/or the service as a whole** to treat the information they provided sensitively and respectfully was a barrier.

The same number (44 – 36%) said **concerns about confidentiality** of the information they provided were a barrier.

A third said a **lack of consistent relationship with staff** and a service contributed to them feeling less able or willing to share monitoring information.

Just less than a third (31%) said a concern was **not understanding how the information would be used** by the service

1 in 4 respondents said a lack of clarity about the reason for the question being asked meant they were **not sure what level of detail to share**

More than 1 in 5 respondents cited that **fear of discrimination based on their gender** was a barrier

14% cited **a lack of opportunity to update a service on changed gender, sexual orientation or trans status** was a barrier to properly engaging with monitoring

Nearly half of those whose gender does not match the gender they were assigned at birth said that **fear of discrimination based on trans status was a key barrier** to sharing monitoring information

A further 14% (17) of respondents stated **fear of discrimination based on being trans** as a barrier. Given that 25% of overall survey respondents said their gender did not match the gender they were assigned at birth, a total of **47% of trans respondents said fear of discrimination based on trans status was a barrier.**

While only one intersex person responded to the survey, it is of note that they stated that they had **concerns of being discriminated against as an intersex person**, and that this was a barrier.

15% said they experiences none of these concerns or barriers

"They make assumptions about the kinds of bodies of people who I have sex with. E.g. if I say I am a gay woman, they assume no one I have sex with has a penis, which is wrong. They then don't give me important information about safe sex because they assume it's irrelevant."

Comments

Some provided further comments on barriers. These included:

- *"Not being believed by staff."*
- *"Public nature of some settings where this may be asked"*
- *"No interest shown, not been asked"*

Community comfort levels with monitoring

We asked respondents how comfortable they would currently feel sharing information about, sexual orientation, gender identity and/or trans status with their GP surgeries versus council services.

- While the majority (74%) said they would be either "very" (44%) or "somewhat" (30%) comfortable sharing this information with their GP surgery, this number dropped to less than half, (48%) in the case of council services.

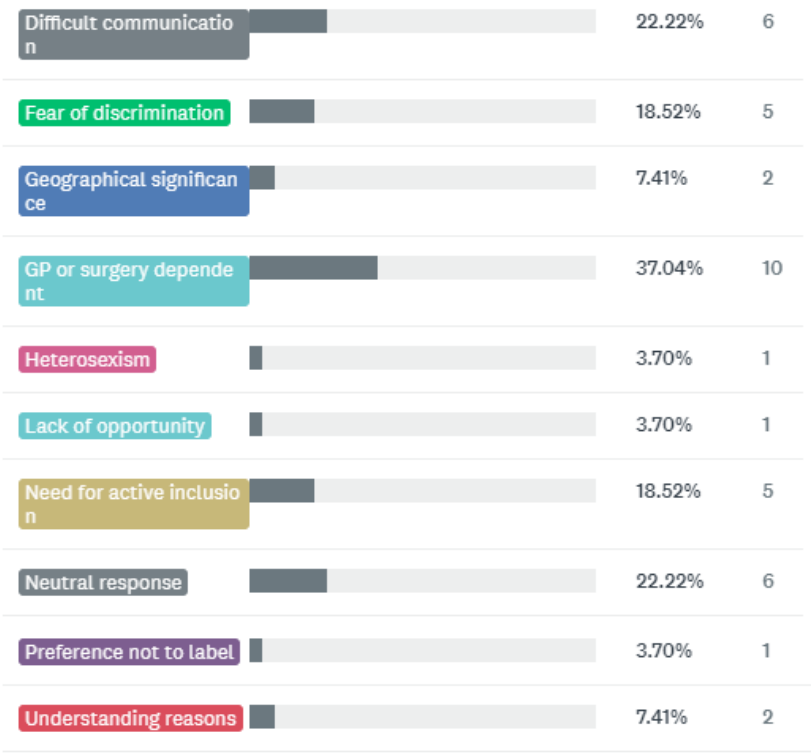
*74% of LGBTQ+ people were currently **'somewhat' or 'very' comfortable** sharing monitoring data in a healthcare setting, but this number dropped to 48% in council settings*

- Reflecting this, 14% said they would feel either “somewhat” (9%) or “very” (5%) uncomfortable sharing monitoring information with their GP, versus 31% for council services, with 21% feeling “somewhat” and 10% “very” uncomfortable.
- Although there was an overall more negative response to sharing in council settings, the responses were distributed more evenly than with GP settings, where more polarised responses and less neutrality was reported. 9% felt neutral about sharing information with their GP, while 18% felt neutral about sharing this information with council services.

*14% of LGBTQ+ people were currently **‘somewhat’ or ‘very’ uncomfortable** sharing monitoring data in a healthcare setting, rising to 30% in council settings*

Comments

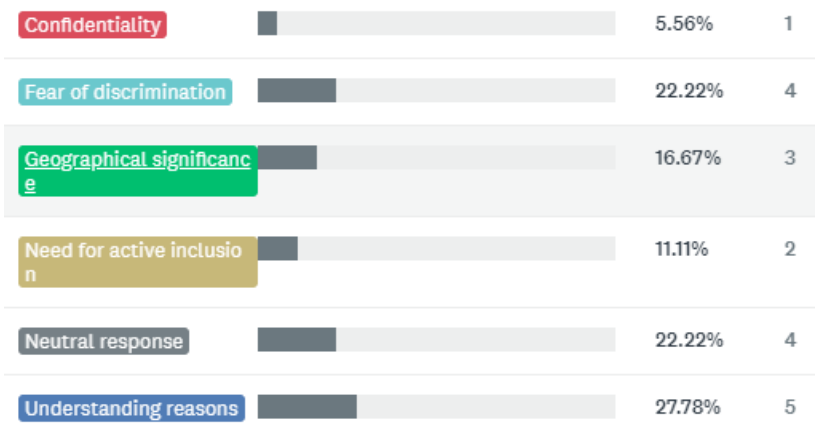
Respondents also provided comments, which raised the following key issues in relation to their levels of comfort sharing information **in a healthcare setting.**



- A notably common response (37% of comments) was that it depended greatly from surgery to surgery, and clinician to clinician, with some respondents stating that they relied on recommendations from others.
- More than one in five were concerned about difficult or “awkward” communication with staff
- Nearly 2 in 10 stated fear of discrimination as a key concern
- Nearly 2 in 10 mentioned a need for active inclusion, either in terms of having had a positive experience of this, or having felt less comfortable due to a lack of visible inclusivity in the surgery.

Respondents also provided comments, which raised the following key issues in relation to their levels of comfort sharing information with **council services.**

- Nearly 30% stated understanding the reasons for monitoring as a key consideration in their level of comfort sharing monitoring information with a council service
- More than 2 in 10 said fear of discrimination was an inhibiting factor



- One respondent said they would be concerned about confidentiality
- 17% of comments mentioned something of geographical significance, in relation to Brighton being a perceived as a relatively safe place
- More than 1 in 10 comments made reference to some need for an active and visible commitment to LGBTQ+ as important in relational to their comfort level

Community awareness and understanding of monitoring

We asked respondents about their current levels of awareness vis a vis reasons for monitoring sexual orientation, gender and trans status. 122 respondents answered this question overall, and the following reasons were provided.

ANSWER CHOICES	RESPONSES	
To better understand the numbers of LGBTQ service users	81.15%	99
To better understand the issues LGBTQ service users are facing	73.77%	90
To better understand LGBTQ health needs	76.23%	93
To provide an opportunity for service users to discuss issues relating to their sexual orientation, gender identity or trans status	53.28%	65
To inform the service offered, such as additional signposting options	54.92%	67
In order for services to show they are complying with equalities laws and policies (e.g. Equality Act 2010)	68.03%	83
I was not aware of any of these reasons for monitoring	9.02%	11
Other reason(s) not listed (please comment)	7.38%	9
Total Respondents: 122		

- The overall level of self-reported understanding of monitoring appeared to be very good. Only around 1 in 10 respondents were not aware of any of the provided reasons for monitoring. However, this seemed to contrast with many of the comments provided throughout the survey, which indicated a widespread confusion and lack of understanding about the reasons for monitoring.

- Although the mostly widely known reason for monitoring was for numerical data on prevalence of LGBTQ service users, most respondents also understood that monitoring could be used to understand the issues LGBTQ service users are facing (around 7 in 10) and to gain a better understanding of LGBTQ health needs (around 8 in 10).
- Fewer, but still more than half of, respondents understood monitoring as providing an opportunity to discuss issues relating to their sexual orientation, gender or trans status, or to receive relevant signposting based on this.
- Around 7 in 10 understood monitoring to be a way of services showing they were complying with equalities law and policy. However, as discussion through the focus groups revealed, this was not always a positive perception, with some viewing this as an indication of being a "box-ticking" exercise that was not for the patient's wellbeing.

Community preferences with monitoring

We asked respondents which factors would help them to feel comfortable sharing information about their sexual orientation, gender and/or trans status.

ANSWER CHOICES	RESPONSES	
The reasons for monitoring are clearly explained	75.42%	89
Confidentiality is clearly explained	72.03%	85
How the information is stored and used is clearly explained	65.25%	77
There are multiple opportunities to share monitoring information over time - not just a 'one-off'	45.76%	54
s 'LGBTQ+ friendly' by an external awarding body	67.80%	80
eived LGBTQ+ awareness training	72.88%	86
ets and other materials visible in the buil		
	7.63%	9

Around 7 in 10 said they would feel more comfortable knowing that a service had been accredited as LGBTQ+ friendly by an external awarding body

In terms of popularity, the most important factor respondents in making them feel comfortable sharing monitoring information was that **the reasons for monitoring are clearly explained to them**, with 3 in 4 citing this as an important consideration.

More than 7 in 10 said **knowing that staff had received LGBTQ+ awareness training** would make them feel more comfortable sharing information

More than 7 in 10 said understanding **confidentiality** was a key consideration

'What would help?'

"Staff wearing pronoun badges"

"Knowing their LGBTQ+ training is trans and non-binary inclusive"

"Seeing a poster/photo/positive image of people 'like you' is very powerful and a really simple but effective way to communicate inclusion."

"LGBTQ inclusion statement on display and on website"

"LGBTQ materials visible please!"

3 in 4 LGBTQ+ people said that having the reasons for monitoring clearly explained would make them feel more comfortable to share their information

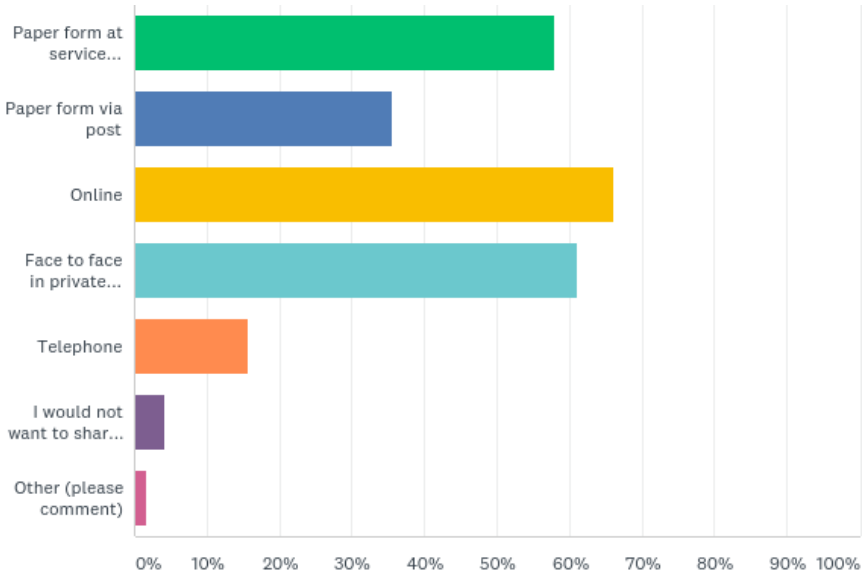
Nearly 7 in 10 said they would feel more comfortable seeing that a service has been **recognised as 'LGBTQ+ friendly' by an external awarding body**

Nearly 7 in 10 said **LGBTQ+-related materials on display**, such as posters and flyers, would help them to feel more comfortable

65% said they would feel more comfortable with an **explanation of how the information would be stored and used**

Nearly half said that they would feel more comfortable knowing that they would have **more than one opportunity to share their information** over time, rather than as a 'one-off'

We also asked respondents **in which format they would be most comfortable** sharing monitoring data:

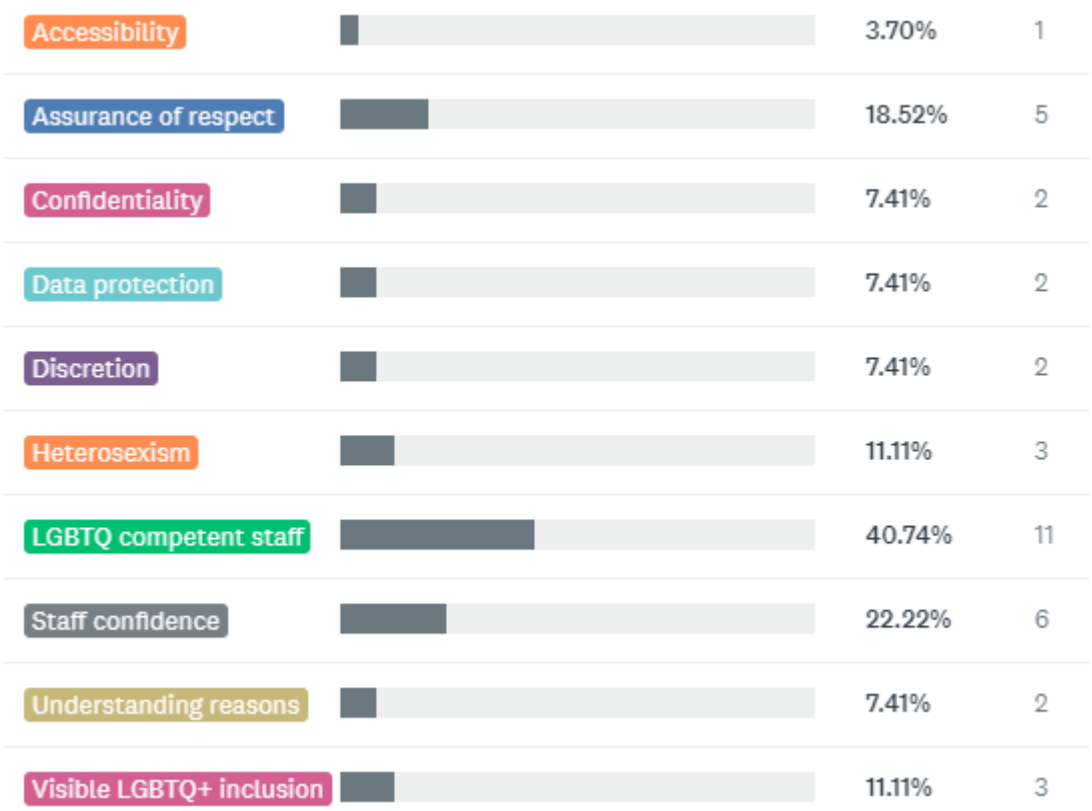


- Approximately as many respondents – around 6 in 10 - were happy to share the information face to face in a private clinical setting (61%) as they were completing an anonymous paper form at the service location (58%).
- The most popular option was to complete the form online – around 7 in 10 said they would feel comfortable with this (66%)
- Only 4% said they would not be comfortable sharing information in any of these ways
- The least popular option was by phone, with only 16% of respondents saying they would be comfortable being asked to provide monitoring information in this way.

We asked respondents what other issues influenced their level of comfort sharing monitoring information in general. The following key themes were raised throughout the comments provided:

"GP practices should be recognised as lgbtq friendly by an official body."

"Knowing that the training that staff have taken part in addressed biphobia and bisexual-specific health risks."



LGBTQ+ Competent Staff

Assurance of respect and LGBTQ confidence of staff came through strongly. Training and a form of independent LGBTQ+ inclusion accreditation were mentioned as factors that would make individuals feel more comfortable.

"Knowing I will be accepted and respected for who I am"

Assurance of Respect

Nearly 2 in 10 comments made reference to a need for assurance that they would be treated with respect

Staff confidence

Knowing that staff feel confident and comfortable asking monitoring questions was also important to respondents, with more than 2 in 10 comments mentioning this

Visible LGBTQ+ inclusion

A visibly LGBTQ+ inclusive environment was also recognised, in terms of staff and materials in the service environment, as making people feel more comfortable and at ease.

Discretion

A need for discretion and confidentiality were a notable theme in comments. This was particularly highlighted by one young person, for whom the risk of having information about their being non-binary shared with family was a key concern.

"Not only the wording, but the way they ask - their manner, tone of voice. Please don't whisper the question like it's embarrassing, because then you make me feel judged. Don't apologise to me about my sexuality!"

"I am underage and not yet out to my family as non-binary, so I wouldn't be able to share this information if I thought that they might find out or if they were present"

Heterosexism

"It makes a positive impact if I see diversity in the front line staff"

Assumptions about individuals' sexual orientations, and especially the assumption that people are heterosexual/straight until established otherwise (heterosexism), and the need for this to be challenged, was another key theme in comments

"In most cases straight people tend to assume I'm a straight woman and I'm probably married to a straight man. I often have to correct people telling them I'm not 'mrs' and I'm not heterosexual I'm a lesbian. […] It's as if many people like to fit us into straight boxes and do that so automatically they aren't even seeing us at all."

Understanding the reasons for monitoring

The need to understand the reasons monitoring questions are being asked was also mentioned throughout comments

Accessibility

One comment made specific reference to the need for monitoring to be asked in a clear, accessible way.

Summary of findings

LGBTQ+ people face significant barriers to sharing monitoring information.

The survey and focus group have demonstrated that LGBTQ+ people face significant barriers to monitoring. This is both in terms of encountering a lack of options that sufficiently reflect LGBTQ+ diversity, and also the environment and context in which monitoring questions are asked, which are

not always LGBTQ+ inclusive. This contributes to a lack of confidence and comfort engaging with staff and services as a whole.

Furthermore, concerns about clinical staff in healthcare settings making assumptions about sexual practices and partners is a key barrier for many LGBTQ+ people to feeling comfortable providing monitoring information, particularly about sexual orientation. There are also concerns that, where information is used to guide clinical intervention (such as sexual health advice), this may be inaccurate and based on incorrect assumptions, risking poorer health outcomes for these patients.

It was also found that there are greater barriers to monitoring for trans and/or non-binary people. This is due to Sexual Orientation options that are limited to reflecting binary gender, which may not be meaningful or helpful for many non-binary individuals. Gender monitoring also needs to be thought about carefully so as to meaningfully include and represent trans and non-binary people.

Under the right conditions, LGBTQ+ people are happy to share information about sexual orientation, gender and trans status

Throughout the survey and focus group, a strong finding was that community members were happy to share information about their sexual orientation, gender and trans status, provided it was conducted in a respectful and inclusive way, and that the reasons for monitoring were well understood. Staff levels of comfort and confidence was of great importance, with the main sources of discomfort coming from staff members' perceived discomfort with asking, or with concerns about being at risk of facing discrimination, all of which could hopefully be addressed with training. Many would actively like to share this information and were frustrated by the lack of opportunity to do so.

In particular, lack of transparency or clarity about the reasons for monitoring were said to feed mistrust and decreased confidence engaging with a service, whereas a positive understanding of the reasons and value of monitoring would have an opposite, positive effect on experience.

Monitoring is a valuable engagement opportunity

When asked well, monitoring sexual orientation, gender and trans status can be an important *opportunity to positively engage* LGBTQ+ service users and patients, by demonstrating active and positive inclusion. When asked poorly, or when the reasons for monitoring were not clear, however, the opposite was true. This is a particularly valuable opportunity given many LGBTQ+ community members' histories of difficult relations and experiences with healthcare providers and council services.

Of note through the survey and focus group was a sense that neutral experiences are considered positive. For many LGBTQ+ people, having an interaction in relation to their sexual orientation, gender or trans status where simply nothing bad happened was considered positive, even when the situation was neutral, and nothing particularly 'positive' happened.

Monitoring also provides an opportunity for individuals and groups whose gender, sexuality and trans status are often ignored or not considered to be heard. Such as older people, those with disabilities, and those with learning difficulties.

LGBTQ+ people are less confident sharing monitoring information in council than healthcare settings

The survey results indicated that there were considerably higher levels of comfort and confidence engaging with monitoring in healthcare settings as compared with council settings. The reasons for this were not demonstrated in the focus group or survey. However, given that key concerns and

barriers in both settings were a fear of discrimination based on sexual orientation, gender, and trans status, we could speculate that there may be a feeling that the consequences of this might be more serious in council services.

Individuals will respond differently depending on how the data will be used

Both the survey and focus group strongly found that people will provide different responses about their sexual orientation, gender or trans status depending on their understanding of how and why the data is being collected and used. This was particularly the case in the context of healthcare settings, where community members said it was important to know whether the information was for statistical purposes only, or if it was being treated as clinically significant information in the case of healthcare services.

Sexual orientation, gender and trans status monitoring work best when done together

Feedback from the community through the survey and focus group strongly suggested that sexual orientation, gender and trans status should all be recorded in conjunction in order for any one of these individual characteristics to be meaningfully understood: personally, demographically and clinically.

However, even with all of this information, healthcare providers should not make assumptions about sexual practices and partners, or about sexual health and family planning needs. For example, lesbian patients may still require contraception and family planning advice, and can still become pregnant.

Healthcare Providers: SOGITS Monitoring Consultation

Consultation summary

As it became apparent that many of the issues and challenges related to monitoring were shared across the healthcare sector, this aspect of the engagement evolved over the course of the consultation period from including GP practices only, to opening to include all primary and secondary healthcare services in Brighton & Hove.

Meetings

1-1 meetings

As part of the consultation, and in preparation for the design and launch of the survey, LGBT HIP reached out to and arranged meetings with Practice Managers and relevant other practice team members in three cluster three GP practices. These practices were chosen because they had already undertaken work with LGBT HIP around LGBTQ+ inclusivity as part of the Inclusion Award, which included sexual orientation, gender and trans status monitoring as part of its training and accreditation package. This meant they would have 'before and after' insight into a process of engaging with monitoring and other practices to improve LGBTQ+ inclusivity.

The intention of these meetings was to have the opportunity for more in-depth conversations around some of the key issues with GP surgeries who were already engaged around issues of LGBTQ+ inclusivity, and to discover some of the key issues that could be addressed on a larger scale in the survey.

Good will towards monitoring and LGBTQ+ communities

It was reassuring to find that all surgeries met with expressed good will towards the idea of monitoring, with the right information, guidance and resources. Several practice managers also expressed the view that, as healthcare providers within Brighton and Hove, they felt they had a particular responsibility to be inclusive to the LGBTQ+ community, due to the prevalence and visibility of these communities in the city. However, it was also of note that a general need for further training and awareness-building around LGBTQ+ issues and monitoring specifically was raised throughout all three meetings, as discussed below.

E&D vs. medical monitoring data

One of the key themes that arose throughout all three meetings was the unique confusion of monitoring in a healthcare setting: due to the medical nature of services, a perception prevails that monitoring is just for medical purposes, and is only relevant when a characteristic relates directly to a patient's medical issues. The potential uses of monitoring for 'equality and diversity' purposes for LGBTQ+ people were not widely understood.

As such, rather than developing monitoring mechanisms, some services said they relied on using 'read codes' to add information to patient record, for example about being trans, but this only occurs when this has specifically come up as a clinical issue with patients, so doesn't capture demographics.

This echoed issues that arose in the LGBTQ+ focus group, where participants expressed trepidation about providing information due to not knowing whether it was for their medical record or for general, anonymous E&D monitoring purposes.

IT/ data recording challenges

IT issues were another common theme throughout, with all three surgeries reporting rigidity of clinical systems and a lack of consistency across platforms presenting issues for accurate and consistent data recording. As such, even if data was carefully collected using the surgery's own forms, this information could be lost at the recording stage.

For example, one surgery noted that the platform EMIS offers 'male' female' or 'intermediate' as options for gender. There was confusion expressed over the meaning of the 'intermediate' option, and a perception that this might be intended for non-binary patients.

It was noted that a gender neutral 'Mx' salutation options had become available on EMIS in recent months, but that there was still nowhere to record patients pronouns, limiting the value of this option.

Likewise, the common platform System 1 offers only 'male, female, not specified'. In this instance, there was discussion of instances in which non-binary patients were listed as 'not specified'.

Again, relying on 'read notes' emerged as a common practice, in the absence of monitoring information. These might be used, for example, where patients have they/them pronouns or have identified themselves as trans to healthcare providers through the process of their care. However, this information was gathered on an ad hoc basis.

The standard NHS GMS1 form, which all patients receive, also only offers binary sex options, and no 'Mx' option. This can create issues regarding a lack of consistency of recorded patient data.

Lack of clarity about the reasons for monitoring

A key barrier identified was staff not knowing the purpose of collecting the data. Indeed, a general lack of understanding of the use and value of monitoring sexual orientation, gender and trans status, from both E&D and patient medical perspectives, was expressed across surgeries.

It is understandable that service management and their staff would be reluctant to conduct monitoring without an understanding of the value of this. As one practice manager put it, "there's nothing clinical staff hate more than collecting information for no reason". However, it was also apparent through the meetings that health inequalities for LGBTQ people were not yet widely understood, and that this contributed to a lower perceived value of monitoring for understanding patient needs and the relationship of monitoring to services' PSED responsibilities.

Time/ resources

Surgeries expressed feeling challenged and overwhelmed by workloads, and expressed that, amidst this, making monitoring a priority would be a challenge.

Audits were named as a key source of work, with some expressing a perception that monitoring might equate to 'yet another audit'.

There was also a perception that surgeries were already being asked to perform duties outside of their core contract, and that some surgeries may perceive monitoring in this way.

Lack of awareness of NHS SOM information standard

No surgeries met with were yet aware of the NHS Sexual Orientation Monitoring standard, its content or implications for monitoring. Information on the standard and the accompanying 'Good Practice Guide' was

Staff confidence

Staff confidence asking/ answering Qs about sexual orientation, gender and trans status was raised as a key issues throughout the meetings. While it was reported that staff felt reasonably comfortable following the inclusion award training, there was still an enduring fear of 'getting it wrong', which was raised throughout, and staff this was impairing the quality of interactions with patients, or causing staff to avoid asking monitoring questions. There was a common perception that any misstep may cause great offense to patients, contributing to tentativeness and avoidance in addressing LGBTQ monitoring.

Concerns around acceptability

Perceptions that the questions would not be acceptable to patients was also an issue raised. A connected concern was not knowing how to respond when patients challenged the question or asked why it was being asked.

Longitudinal data issues

All of the surgeries collected monitoring data at the point of service registration only, reportedly a common practice across surgeries.

This means that a great deal of patient data is lost:

- Patients whose sexual orientation, gender or trans status has changed since registration or will change again in future. This issue is particularly acute for trans and/or nonbinary individuals when joining a surgery during a period of transition
- Data of patients who joined the service prior to the introduction of monitoring will be lost

Concerns were raised about ongoing monitoring or monitoring on multiple occasions due to time and resource constraints.

Motivation

A lack of external impetus was also raised. One surgery noted that in the past, they were required to report monitoring info back to their PPG, but this was no longer the case. There was a lack of clarity over whether the NHS SOM guidelines were mandatory, and an expression that it would be difficult to prioritise monitoring when surgeries were already struggling to meet mandated responsibilities, such as auditing.

Legal issues

There was confusion over whether trans patients needed to provide a deed poll or GRC in order for their correct name and gender to be recorded. One surgery said the Health Authority had claimed that this was the case, and that they had relayed this information to patients. As the Healthcare providers survey and LGBTQ+ focus group revealed, this is a somewhat prevalent view. However, this practice is in fact illegal, and has been addressed by the past HIP Consultation on the Inclusion award (or 'Kitemark Scheme'). However, these surgeries were concerned they were doing something illegal by changing names and genders, and that these would not be amended via the Department for Health Medical Records.

Trans-specific guidance

Some confusion regarding processes for patients in the process of transitioning was also expressed.

Of particular urgency was a need for clarity on procedures for managing records of trans patients with new records, and particularly whther the old and new records should be merged or kept separate. There was a concern about losing important clinical information on old records, but also

over the legality of transferring information from one record to another. It was emphasised that a clear protocol around this was required.

Furthermore, some surgeries were not clear whether they should keep and record letters from GICs, and whther this information should be recorded. Clinical questions about trans health were also raised through the meetings.

Key needs and recommendations

Through the meetings, several key needs and recommendations for meeting these were expressed, including:

Training

A need for further LGBTQ+ awareness and monitoring related training was expressed. It was suggested that this could be through a protected learning session from the CCG.

Resources

In particular, a need for clear written guidelines was expressed, and that 'Good practice guides' would be a valuable resource for improving both LGBTQ+- and monitoring- awareness.

Operational and systemic changes

Through the meetings, management and staff made calls for standardisation and communication between agencies, as the current situation presents great challenges for recording and communicating patient information about sexual orientation, gender and trans status clearly and consistently. It was also proposed that the CCG could provide codes that reflect new sexuality, gender and trans status options for the purposes of coding, as used in audits.

LGBT Foundation/ NHS England SOM Meeting

Representatives from the LGBT Foundation and NHS England hosted a meeting to discuss the new Sexual Orientation Monitoring standard in London in March 2018. The meeting was predominantly attended by London-based Clinical Commissioning Group representatives and Equality and Diversity leads within the statutory healthcare sector.

Some of the discussions and outcomes of this meeting were of use and relevance for the purpose of this consultation, in terms of understanding some of the perceptions and challenges regarding SOM and monitoring in general. The following key themes emerged through the meeting:

- There was an overall feeling of disappointment that the SOM Information Standard doesn't mandate data collection, as without this push it is unlikely to be a priority for those responsible for implementation. This is also the case for updating IT systems, as it is not seen as a priority and updates have cost implications.
- Success has been had where senior staff members have acted as champions and helpful departments have been on board with monitoring and pushed for implementation. Commissioners could put pressure on this by making it part of standard contracts, but are unlikely to do so without pressure from NHS England as it will not be seen as a priority.
- For those who were willing to update the system there was still some confusion, and staff were told it was not possible. There was a question of whether NHS Digital could provide additional support or whether a case study could be used to help with this. It was asked whether it might be possible to explore requesting a mandate from NHS England to update IT systems to include SOM.
- The benefits of collating information needs to be communicated better and more widely. The group highlighted that within the system, and particularly for those asking demographic

questions (often reception staff) there is a general lack of understanding of why monitoring in general is important which can often lead to poor return rates. Patient experience should be highlighted and can be more impactful than data. The Equality Act 2010 can be used as a lever for implementing SOM.

- Data collated should be made available nationally, for reflection and quality improvement.

Healthcare Providers' Survey

The target audience of the survey was primary and secondary healthcare professionals working in practices, agencies or organisations based in Brighton and Hove. This included both clinical and non-clinical staff.

The survey was live over a three week period across February and March 2018. In addition to promotion through the LGBT HIP newsletter and the LGBT Switchboard's Facebook and Twitter accounts, the engagement topic and survey was promoted via email: through the Brighton and Hove CCG's weekly practice bulletin; by circulating through the Equip group list; and via direct email to meeting participant practice managers.

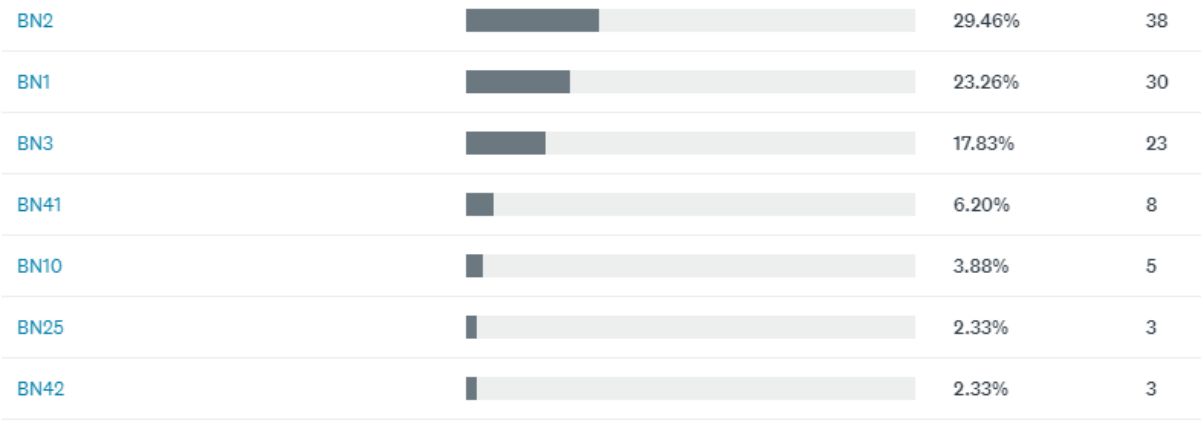
Question 1 of the survey was an exclusion question designed to filter out any respondents who were not healthcare professionals based in Brighton and Hove.

148 individuals responded to the survey, and of these **145 satisfied the criteria of the exclusion question and went on to complete the survey.**

Demographics

Q2: Neighbourhood: 129 answers

We asked respondents to provide the first part of their postcode. 29% (38) of respondents were based in BN2, 23% (30) in BN1 and 18% (23) in BN3. 8 (6%) were located inBN41, 5 (4%) in BN10 and 2% (3) each in BN25 and BN42.

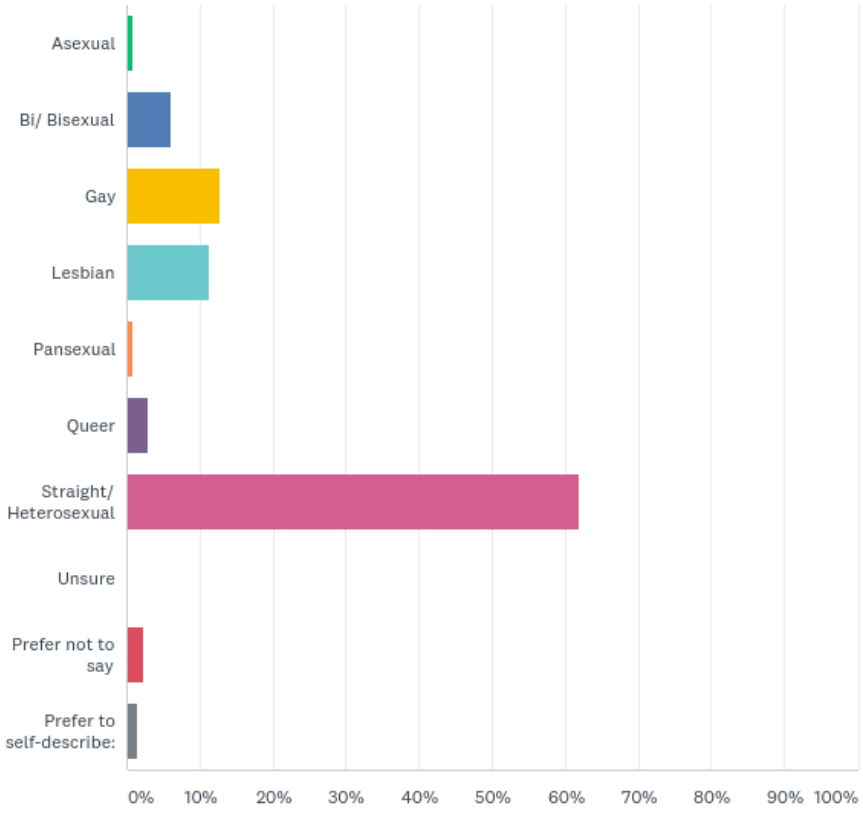


Q3: Age: 133 answers

We asked respondents : 'What was your age at your last birthday?' The largest proportion of those responding were aged 45-54 (33.83%), followed by 35-44 (21.8%), and 55-64 (21.05%). 18.08% were aged 25-34 and only 4.51% were aged 18-24. No respondents were aged 65 or over.

ANSWER CHOICES	RESPONSES	
17 or under	0.00%	0
18-24	4.51%	6
25-34	18.80%	25
35-44	21.80%	29
45-54	33.83%	45
55-64	21.05%	28
65-74	0.00%	0
75+	0.00%	0
Prefer not to say	0.00%	0
TOTAL		133

Q4: Sexual Orientation: 134 answers



We asked respondents "How would you describe your sexual orientation?" Participants were provided with a free text field to provide their preferred term under 'prefer to self-describe'. The majority of respondents identified themselves as 'heterosexual/ straight', at 61.94% (83). 48 respondents identified somewhere under the LGBTQ+ umbrella (35.83%), with the largest proportion of these identifying as gay (12.69%, 17), followed by lesbian (11.19%, 15) and bisexual (5.57%, 8). One participant identified as asexual, one as pansexual, and four as queer. No respondents selected 'unsure'. Of those who preferred to self-describe (2), one provided "gay woman" and the other 'bisexual in a heterosexual relationship'. Three participants chose 'prefer not to say'.

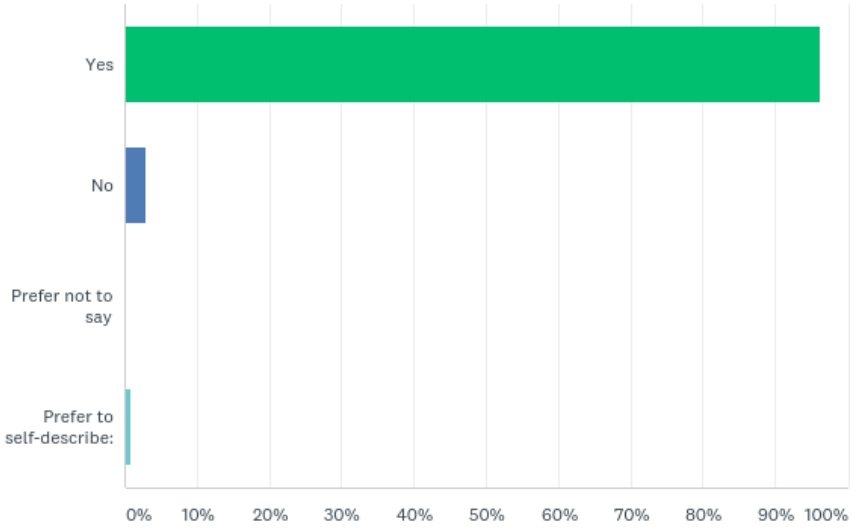
Q5: Gender: 134 answers

We asked respondents "How would you describe your gender?" We offered the options 'female/ woman (including trans woman)', 'male/ man (including trans man)', 'non-binary', 'agender', 'unsure', 'prefer not to say', and 'in another way', with a free text field in which to self-describe. The majority of respondents identified as female/ women (79.1%, 106), followed by male/ men (17.91%, 24). 2.24% (3) respondents were non-binary, and one (0.75%) chose 'prefer not to say'.

ANSWER CHOICES	RESPONSES	
Female / woman (including trans woman)	79.10%	106
Male / man (including trans man)	17.91%	24
Non-binary	2.24%	3
Agender	0.00%	0
Unsure	0.00%	0
Prefer not to say	0.75%	1
In another way:	0.00%	0
TOTAL		134

Q6: Trans Status: 135 answers

To discern the trans status of respondents, we asked "Is your gender the same as the gender you were assigned at birth?" The vast majority of respondents selected 'yes', identifying themselves as cis-gender, at 96.3% (130). 2.96% (4) answered 'no, positioning themselves as trans. One respondent preferred to self-describe, and stated "I wasn't assigned, I was observed", indicating that they disagreed with the terms of the question.



Q7: Intersex Status: 133 answers

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." The vast majority of respondents selected 'no' (94.74%, 126). One selected 'yes' (0.75%). 2.5% (2) each chose 'unsure' and 'prefer not to say'. 2 also selected 'prefer to self-describe', but both expressed confusion about what question was asking. However, these did not indicate whether the lack of clarity was related to the question structure or the meaning of the term intersex.

ANSWER CHOICES	RESPONSES	
Yes	0.75%	1
No	94.74%	126
Unsure	1.50%	2
Prefer not to say	1.50%	2
Prefer to self-describe:	1.50%	2
TOTAL		133

Q8: Disability: 134 answers

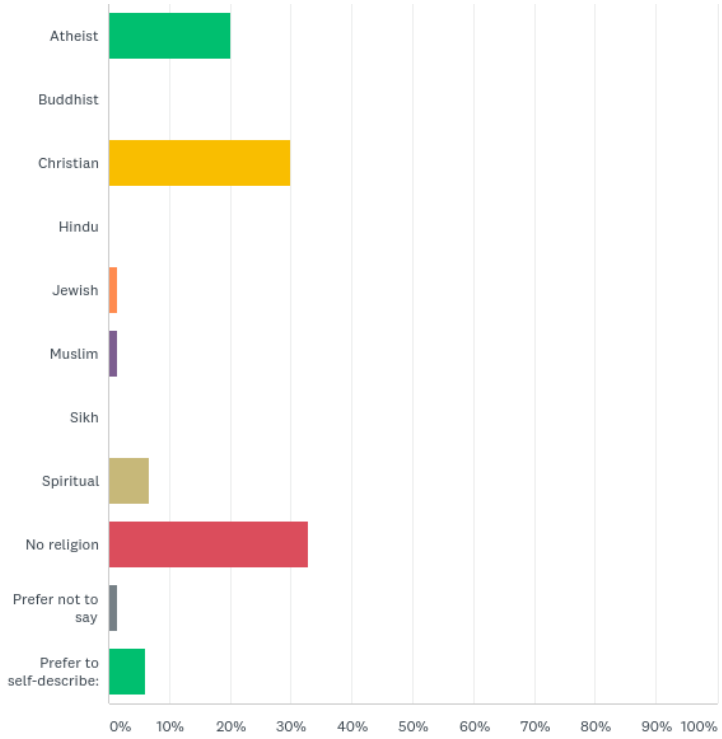
We asked respondents "Do you live with a health condition, impairment, learning difference, or neurodivergence that shapes your day to day activities?" 65.67% (88) of respondents reported that they had no known health condition, impairment, learning difference or neurodivergence. Of those who did have some form of the above, mental health difficulties were the most prevalent (17.16%, 23), followed by long-term health condition or illness (11.94%, 16) and those with a specific learning difficulty (3.73%, 5). One (0.75%) stated they had a physical impairment or mobility issue, and one a

ANSWER CHOICES	RESPONSES	
No known health condition, impairment, learning difference, or neurodivergence	65.67%	88
Long-term illness or health condition (e.g. cancer, chronic heart disease, diabetes, epilepsy, HIV)	11.94%	16
Mental health difficulty (e.g. addiction, anxiety, depression, eating disorders)	17.16%	23
Physical impairment or mobility issues (e.g. difficulty using your arms, using a wheelchair)	0.75%	1
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)	2.24%	3
Social or communication condition (e.g. a speech and language impairment, Asperger's syndrome/ other autistic spectrum condition)	0.75%	1
Specific learning difficulty (SpLD) (e.g. AD(H)D, dyscalculia, dyslexia, dyspraxia)	3.73%	5
Blind or visual impairment that can't be fixed with glasses	0.00%	0
D/deaf or a hearing impairment	1.49%	2
Prefer not to say	1.49%	2
Prefer to self-describe:	2.24%	3
Total Respondents: 134		

social or communication condition. 1.49% (2) participants identified as D/deaf or having a hearing impairment. 2 participants chose 'prefer not to say'. Three respondents chose to self-describe. Of these, two described long-term health conditions, and one said they had no known condition.

Q9: Religion, faith and spirituality: 134 answers

We asked respondents "If you have a religion, faith, or spirituality, how would you describe it?"



52.99% (71) reported that they were either atheist (20.15%, 27) or had no religion (32.84%, 44). 29.85% of respondents (40) identified as Christian. 1.49% (2) respondents selected Jewish and the same number for Muslim. 6.72% (9) respondents chose 'spiritual', and 8 (5.97%) chose to self describe. Of these, three said 'agnostic' and two said 'pagan'. The remaining three said 'atheistic satanist', 'nearest to Christian', and 'humanist'. No respondents identified as Sikh, Hindu or Buddhist.

Q10: Ethnic Origin: 135 Answers

We asked respondents: "How would you describe your ethnic origin?"

The vast majority of respondents identified themselves as white British, at 80.74% (109). 5.19% (7) were white European. 11.1% of respondents were from a BAME background.

Each of the following ethnicities was represented by one respondent (0.74%) each only:

- Asian/ Asian British: Bangladeshi
- Asian/ Asian British: Chinese
- Asian/ Asian British: Indian
- Black/ Black British: Caribbean
- Black/ Black British: Other black background
- Mixed: White and black
- Mixed: Asian
- Mixed: Caribbean
- White: Irish
- White: Other white background.

One respondent stated they would prefer not to say, and 4 (2.96%) chose to self describe. Of these, answers provided were:

- 'white british'

- ‘black american’
- ‘british with south American background’
- ‘white/ latino’

About respondents’ roles and services

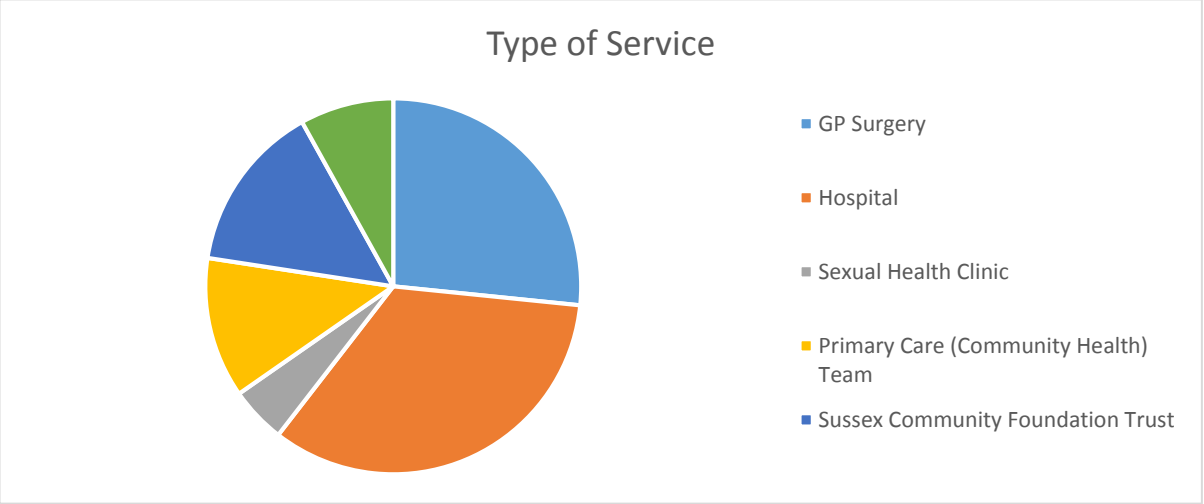
These questions were designed to provide a picture of the types of roles respondents had, to help us understand what the different needs, opportunities and challenges might be in relation to monitoring within different roles.

About respondents’ services

Respondents identified themselves as working within a range of different types of service. The most prevalent of these were hospital settings (42), followed by GP surgeries (33), the Brighton & Hove Primary Care/ Community Health Team (15), the Sussex Community Foundation Trust (18), Sexual Health Clinics (6) and several other individual organisations and services (10). Some respondents worked across two or more locations.

Individuals from 16 GP surgeries responded, all three sexual health clinics (Claude Nicol, Wish Park and Morley Street), and individuals from all major hospitals in the area, including the Royal Sussex County Hospital, Brighton General Hospital, Royal Alexandra Children’s Hospital Princess, Royal Hospital, Sussex Eye Hospital and all Brighton & Sussex University Hospital sites.

This combination of a range of primary and secondary/ acute care services offers an opportunity to understand monitoring practices across a range of settings.

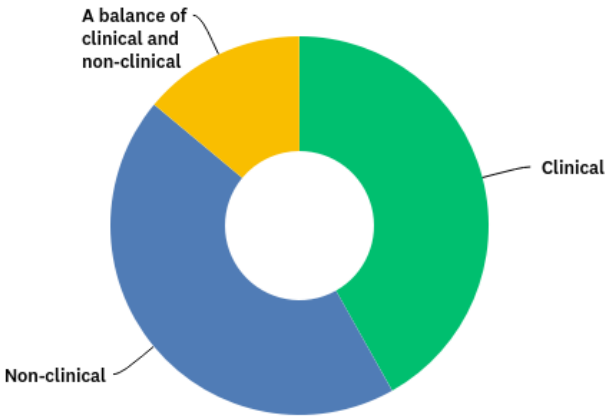


About respondents’ roles

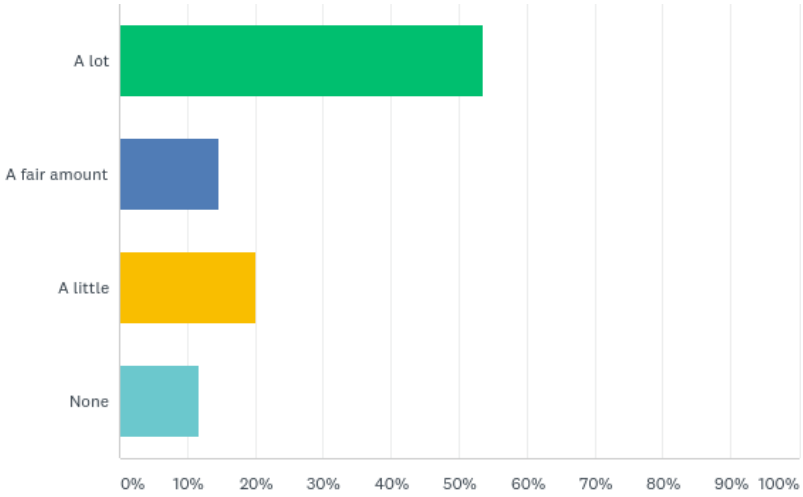
Respondents represented a good range of frontline/ patient-facing and ‘behind-the-scenes’/ operational roles, offering an opportunity to hear insights into the relational/ interactional aspects of collecting monitoring information, as well as the practical aspects of recording and analysing data.

A fairly even balance of clinical (41.86%, 54) and non-clinical (44.19%, 57) staff responded. 13.95% (18) of respondents roles involved a balance of clinical and non-clinical work. Clinical roles included

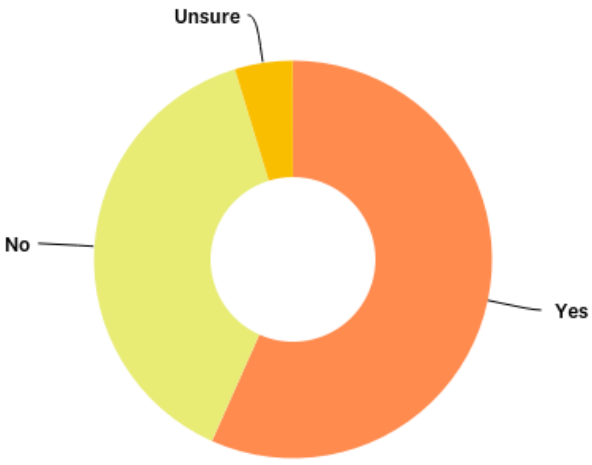
hospital doctors, consultants, psychotherapists, general practitioners and nurses, while the majority of non-clinical roles were held by reception, administrative, and managerial staff.



88.38% of respondents' roles involved direct interaction with patients. Of these, most (53.49%, 69) involved 'a lot' of patient/ service user contact, while 14.73% (19) had 'a fair amount'. 20.16% (26) had 'a little' and 11.63% (15) had none.



The majority of respondents (59.69%, 72), had direct responsibility for collecting, recording, or analysing demographic monitoring information as part of their role. 38.58% (49) said they did not, and 4.72% (6) were unsure whether they did this in their role.



Monitoring practices

Due to the wide range of services represented by respondents to the survey, and the complexity of departments within these, it was not possible through the survey to capture and compare the *actual monitoring practices* of individual healthcare services, as in the types of questions and answers offered.

However, the survey did capture individual respondents' *knowledge, understanding and awareness* of the monitoring practices of the services where they work, and some indication of the prevalence of different forms of monitoring. A further piece of work would be required to audit the actual monitoring practices of the wide-ranging healthcare services in Brighton and Hove.

Characteristics monitored

We asked healthcare providers about the characteristics their services monitor, and provided a brief definition of each term.

- The characteristic with the highest rate of awareness of monitoring was gender, with 6/10 respondents aware of their service monitoring this.
- 58% said their service asked a monitoring question requesting patient 'sex'
- Less than a third of respondents said their service monitored sexual orientation
- 1 in 5 respondents were unsure about which characteristics were monitored
- 3 in 4 respondents said their service did not monitor trans status
- 94% of respondents said their service did not monitor intersex status
- Around 9% said their service monitored none of these characteristics

'Gender options'

- The most common options provided for a question asking about 'gender' were the binary sex terms 'male' and 'female'
- Over 1 in 5 respondents said their service offered 'transgender' as an option in gender, alongside traditional/ binary male/female options
- None offered 'agender'
- 8.57% of respondents said 'non-binary' was offered as an option
- 1 in 10 said some form of 'Other' option was available
- 4.29% offered 'prefer to self describe' or equivalent
- 13% offered a free text field
- 2.86% (2) offered "Female (including trans woman)/ Male (including trans man)"

'Sex' options

- Only one respondent said their service offered an intersex option
- Only three respondents said their service clarified that the sex being requested
- Issues with sex being 'assumed' based on information provided, not patient's self-identification
- 'Not specified' is a common option
- 'Non-binary' being included under sex in some cases

'Sex' and 'Gender' monitoring issues

- There was confusion expressed about the difference between 'sex' and 'gender', and as a result some lack of clarity about which characteristic was being monitored.

- IT system – many respondents flagged that their database offers 'sex' only, so this term is used interchangeably to mean 'gender'.

"We use a computer generated data base that only collects information about a person's sex. We do not have a way of capturing the rest of the information and this means we miss out on having discussions on someone's orientation for example, unless it is obvious if someone is living with another of the same sex.

"I feel we are trying to fit our patients into too few boxes that don't reflect their life choices and the diversity of people we see in the Community, which I think is a real shame. It also stops us having open discussions about how patient's see themselves, which are often life-defining for them as these issues become side-lined.

"The richness of diversity of patients living in our Community is not reflected in the data that is produced and I feel we are doing a disservice to our Communities."

'Sexual Orientation' options

- None offered 'queer' as an option
- 1 in 10 offered 'other' or equivalent
- Some said 'homosexual' was offered as an option. It is worth noting that previous consultations (such as the Inclusion Award 'Kitemark scheme' consultation) have found that many LGBTQ+ people find this terminology outdated and pathologising.

Trans status options

- Only 1 in 10 respondents said their service offered separate questions for gender and for trans status
- 35% said they were 'unsure' whether separate questions were offered, and the remaining

Analysis of monitoring data

While just over 1 in 10 said their service did analyse monitoring data, nearly 1 in 4 said they believed their service did not. Furthermore, more than half of respondents weren't sure whether their organisation did so.

Through the survey comments, one respondent shared their disappointment about a lack of equality and diversity use of monitoring, and a desire for services to make positive changes in this area:

"As far as I am aware they don't analyse this. This is disappointing as the Equality and Diversity Training that we all undertake thoroughly and impressively covers this issue and offers links for further information."

Methods of data collection

We asked respondents on what occasions ('When?') and via which methods ('How?') their services currently collecting monitoring data.

When?

- 7/10 at point of registration
- ¼ at point of service delivery
- 1/5 at service user engagement
- 1/10 when logging complaints
- 16% unsure of when this is undertaken

It was also noted by some respondents that patient data is often taken from the patient registration system, rather than from patients themselves. However, this opens potential for the information to be lost in translation, and also means that information may not necessarily match with how patients would self-identify.

How?

- More than 6 in 10: in paper form at the service location
- Approximately a third via an online form
- 4/10 said the information was collected verbally in face to face appointments with clinicians
- 16% said over the telephone
- 1/10 by post
- Nearly 1/5 weren't sure how monitoring information was collected

Communicating rationale of monitoring and confidentiality of data

- Approximately 7 in 10 either weren't sure whether the reasons for monitoring were clearly communicated to service users/ patients, or believed they were not clearly communicated
- Just over 4 in 10 felt confidentiality either wasn't clearly explained, or they were unclear about whether it was or not

Pronouns and titles

While pronouns and titles/ salutations do not form a part of monitoring per se, these were considered by participants in our LGBTQ focus group, particularly trans and/or non-binary individuals, to be an important consideration for their level of comfort and willingness engaging with monitoring.

- 'Mx' gender-neutral salutation
    - Approximately 8% of those who responded said their service offered an 'Mx' gender neutral title
    - Nearly 1/3 were unsure
- Pronouns
    - Only 9% asked patients about their pronouns
    - 6/10 did not and 3/10 were not sure

Attitudes to monitoring

Confidence in asking

We asked respondents how confident they would feel asking patients and service users about their sexual orientation, gender and trans status in an appropriate monitoring context.

- Sexual Orientation
    - 62% of respondents said they were either 'quite' or 'very' confident asking patients about their sexual orientation in an appropriate monitoring context.
    - 15% felt they were either 'not very confident' or 'not confident at all'.

    - The remaining 23% occupied a middle ground ranging between ‘a little confident’ and ‘a little lacking in confidence’.
- Gender
    - 60% ‘quite’ or ‘very’ confident asking patients about their gender in an appropriate monitoring context.
    - 18% felt they were either ‘not very confident’ or ‘not confident at all’.
    - The remaining 22% occupied a middle ground ranging between ‘a little confident’ and ‘a little lacking in confidence’.
- Trans Status
    - 46% ‘quite’ or ‘very’ confident asking patients about their trans status in an appropriate monitoring context.
    - 28% felt they were either ‘not very confident’ or ‘not confident at all’.
    - 26% occupied a middle ground ranging between ‘a little confident’ and ‘a little lacking in confidence’.
- Intersex
    - 33% ‘quite’ or ‘very’ confident asking patients about their intersex status in an appropriate monitoring context.
    - 46% felt they were either ‘not very confident’ or ‘not confident at all’.
    - 21% occupied a middle ground ranging between ‘a little confident’ and ‘a little lacking in confidence’.

While reported levels of confidence asking about these were reassuringly high, these varied across different characteristics, and indicated room for change and improvement. The highest rates of confidence were found among sexual orientation and gender, where approximately 6 out of 10 respondents said they were either ‘quite’ or ‘very’ confident asking patients about these characteristics in an appropriate monitoring context. This dropped to around half (46%) for trans status. For intersex status, however, half said they were either ‘not very confident’ or ‘not confident at all’. However, it was notable that some respondents said their response was based on how they *would* feel “with training” rather than their current level of confidence.

Some comments reflected a view that asking about gender and trans status was a more ‘sensitive’ issue than asking about sexual orientation, partly due to the continued pathologisation of transness and gender dysphoria:

> *“Asking someone if they are gay or lesbian is not the same as asking them if they feel that their gender matches their sex. It is a far more loaded question. Most people never feel the need to consider whether their sex and gender match. Gender dysphoria leads people to question this and it is regarded by many people as a mental illness.”*

Some comments also connected a lack of understanding about the reasons for monitoring with lower confidence, and concerns about the impact on patients:

> “I don't think our service adequately explains how we are going to use the data to improve or monitor the patient experience so I would not want to ask any personal questions unless I was sure of why I was asking them and sure of any help/ support we could offer.”

Understanding, awareness and valuing of monitoring

The need to explain why monitoring data is being collected has been found to be important to patients' level of acceptance of questions, a finding of LGBT Foundation research as well as this consultation's engagement with the local LGBTQ+ community. Research by the LGBT Foundation found that 96% of respondents would be happy to answer a monitoring question about their sexual orientation, as long as they understood why they were being asked.

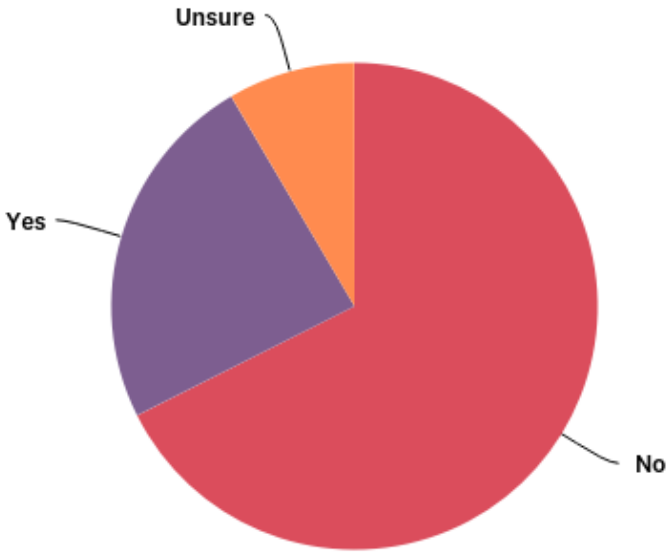
Nearly 7 in 10 respondents were not aware of the new NHS Sexual Orientation Monitoring Information Standard

At present, our research found that just less than half (49%) of healthcare professionals surveyed would feel 'quite' or 'very' confident responding to a patient who asked why monitoring data about sexual orientation, gender identity and trans status is collected. 26% felt they were either 'not very confident' or 'not confident at all', and 25% occupied a middle ground ranging between 'a little confident' and 'a little lacking in confidence'.

NHS SOM Information Standard Awareness

We asked respondents "Were you previously aware of NHS England's new Information Standard on Sexual Orientation Monitoring?"

Of note was the finding that a majority (68%) of respondents were not aware of NHS England's Information Standard on Sexual Orientation Monitoring, released in October 2017 (around 4 months prior to the survey). 8% were unsure, and only 24% were aware of the standard.



Of those who *were* aware of the standard, 17 in 27 respondents said they were lacking in confidence, with 11 of these either 'not very confident' or 'not at all confident'. Only one respondent out of 69 reported feeling 'very confident', and followed up by stating: "But without any intention of doing it unless it is of DIRECT relevance to patient care", reflecting a common theme of doubt and questioning about the relevance and scope of monitoring to patient care, inclusion and health outcomes.

Understanding the reasons for monitoring

We provided respondents with a list of some of the benefits of monitoring and asked which ones they were currently aware of. Although a general lack of clarity about the reasons for monitoring was expressed throughout the survey and through the meetings, just over 1 in 10 said they were not aware of any of the provided reasons for monitoring when surveyed. The remaining responses, listed below, were understood by 5-7 out of 10 respondents.

ANSWER CHOICES	RESPONSES	
To better understand the numbers of LGBTQ patients	53.62%	37
To better understand the issues LGBTQ patients are facing in accessing services	73.91%	51
To better understand LGBTQ health inequalities	68.12%	47
To better understand LGBTQ health needs	63.77%	44
To provide an opportunity for service users to discuss issues relating to their sexual orientation, gender or trans status	60.87%	42
To inform the service offered, such as additional signposting options	57.97%	40
To ensure appropriate information and advice is provided where relevant	56.52%	39
To meet the Public Sector Equality Duty (Equality Act 2010), as a way of demonstrating due regard for LGBTQ patients	55.07%	38
I was not aware of any of these reasons for monitoring	11.59%	8
Total Respondents: 69		

Valuing of monitoring

We asked respondents how important they considered monitoring sexual orientation, gender identity and/or trans status to be in ensuring better health outcomes for LGBTQ patients. Interestingly, despite an ongoing theme throughout the survey of doubt about the value of monitoring to patients, around 8/10 respondents said they considered monitoring sexual orientation, gender identity and/or trans status to be either ‘fairly important’ or ‘very important’ in ensuring better health outcomes for LGBTQ patients. While 9% they were ‘unsure’, none said they considered monitoring ‘not at all’ or ‘not very’ important.

This was an interesting and somewhat anomalous finding, as many respondents expressed a view throughout the survey that they did not understand the relevance of monitoring to patient wellbeing, or perceived monitoring as unimportant. It may be that these respondents selected ‘unsure’, did not answer this question, or that socially desirable answers were provided.

Comments

A need to understand the benefits of monitoring to patients

A message that came through strongly in the comments on this question was the need of healthcare professionals to understand the reasons for monitoring, and to be assured that the data collected would be used in a meaningful way, and to the patient’s benefit.

"I think it depends on the relevance to the service and whether any action is actually taken. We once had to put information about a patient's sexual orientation on a form requesting equipment provision, but when I queried it there was no reason for collecting that data so I didn't fill it in. I think if the data is used to improve outcomes/access then it could be very useful, if it is just a tick box exercise then it is useless"

"I identify as gay and am also a doctor I would obviously support better health outcomes for LGBTQ patients but would hope to achieve this by asking relevant questions not by blindly following a government imperative"

"I need to be persuaded of the value of this. What do service users think?"

"I DON'T KNOW HOW MONITORING 'DATA' IS USED AND NEITHER DO PATIENTS THUS THERE ANNOYANCE RE CONSTANTLY BEING ASKED FOR PERSONAL INFORMATION."

Objection to specifically addressing LGBTQ+ communities for monitoring purposes

Another common theme was that of resistance to monitoring sexual orientation, gender and trans status specifically. This view was expressed on a number of bases, including the perception that doing so would somehow exclude non-LGBTQ patients, unfairly prioritise LGBTQ+ patients, or that these characteristics are not relevant to patient care.

"We should be ensuring better health outcomes for all our patients"

"No more important than other patients"

"I think that better health outcomes are important for everyone regardless of anything."

Concerns about patient acceptance of monitoring

Comments also revealed that some respondents perceived monitoring as irrelevant to their service. In addition, some expressed a perception that these questions are not appropriate for older patients, and may anger others, being considered intrusive and unwelcome.

"I do not see the relevance in relation to the care we provide here […] Many patients would be very annoyed if we were to ask this and many of our patients are elderly"

"I don't agree with collecting this data unless it is of direct relevance to the patient's problems. An inappropriate intrusion"

"Unless it directly relates to patients healthcare I personally feel this would be intrusive, inappropriate and also politically motivated."

Perception that Brighton & Hove has a particular responsibility to LGBTQ+ people

Reflecting some of the views shared in the one-to-one meetings, a commenter stated that Brighton and Hove has a particular responsibility to lead the way in terms of monitoring for sexual orientation, gender and trans status, because of the history, prevalence and visibility of LGBTQ+ communities in the city.

> "Brighton and Hove are areas where there is a high and visible community of such [LGBTQ+] people and we as service providers have a greater responsibility to make an effort to meet their needs."

Challenges to monitoring

We asked respondents what their key challenges were, if any, with regard to **collecting**, **recording**, **analysing** and **actioning** monitoring data.

For each question, we provided a list of some of the common challenges in these areas, provided below, as we understood them, based on the meetings with practice managers and existing research.

Challenges to collecting data

The most common challenges to **collecting** monitoring data were IT system issues (25%), time and resource limitations (22%) and a lack of clarity around how best to ask monitoring questions (22%). Nearly 2 in 10 also said a lack of confidence around language and terminology was also a barrier.

A smaller but still significant number of respondents, more than one in ten, said that the following reasons were also a barrier to collecting data:

- A lack of confidence interacting with patients about LGBTQ+ issues
- Unclear about the reasons for monitoring
- Concerns about alienating non-LGBTQ+ patients
- Unsure about which answer options to offer with questions

Five respondents (out of 63 who responded) said that conflicting information about monitoring practices from different sources was a challenge, and a further four said that confusion regarding the need for deed polls and gender recognition certificates in collecting information was an issue.

20% said they experienced no challenges with collecting monitoring data on these characteristics.

Reflecting a common theme throughout the consultation, comments in this section made frequent reference to a perception of appropriateness and intrusion as a barrier to collecting monitoring information:

"Intrusive questioning and relevance/appropriateness"

"While I don't have any issues with collecting data I know many staff feel we are being intrusive so will not feel comfortable."

"I just don't expect many people to feel completely comfortable or safe to share this information."

One comment recognised a lack of adequately diverse options on forms as a barrier:

"Currently I don't think our forms reflect diversity adequately so collecting data would be difficult."

Some comments from those working with children and young people also acknowledged some of the particular challenges and considerations for monitoring with these groups.

"Our patients range from newborn to 19 years. The question is irrelevant for many, incredibly important for others. For some children and families, the question could be confusing or upsetting, or lead to the parent having to provide explanations based on our monitoring requirements rather than the child's curiosity/emotional readiness. For other children and young people, the question could be a life saver - the first time someone has asked, listened, valued them for who they are"

Challenges to recording

The most common challenge to **recording** monitoring data was IT issues (35%), and around 2 in 10 said time and resource limitations were a key challenge.

A smaller but still significant number of respondents, more than one in ten, said that the following reasons were also a barrier to collecting data:

- A lack of confidence around appropriate language and terminology
- A lack of clarity about the reasons for recording data
- Conflicting information about recording practices

Four respondents (out of 63 who responded) said that conflicting information about monitoring practices from different sources was a challenge, and a further four said that confusion regarding the need for deed polls and gender recognition certificates in recording information was an issue.

21% said they experienced no challenges with recording monitoring data.

Challenges to analysing

Of those who responded (58), the most common barrier to **analysing** data cited was time and resource limitations, at 24%. Nearly 2 in 10 also stated that a lack of clarity about good practice in monitoring data analysis was a key issue.

A smaller but still significant number of respondents, more than one in ten, said that the following reasons were also a barrier to collecting data:

- Unclear about the reasons for analysing monitoring data
- It system issues

Three respondents cited a lack of confidence addressing LGBTQ+ issues/

14% said they had no challenges with analysing monitoring data.

Challenges to actioning

Time and resource limitations were, again, the main challenge to **actioning** the findings of monitoring data analysis, at nearly a third of respondents (32%). More than 1 in 4 (28%) also said they were unclear about the possible actions to take, and the same amount also said they had a need for further support and guidance on good practice for using monitoring data strategically.

14% said they faced no challenges with actioning monitoring data.

Training Needs

Training was identified throughout as a key need, with several commenters stating that "with training" they anticipate they would feel "very confident" collecting, recording, analysing and actioning this demographic monitoring data.

In response to a question asking if they would like to access further training, support or information in regards to monitoring sexual orientation, gender identity and trans status, the vast majority of respondents answered positively.

Of these, 7/10 said in-person LGBTQ+ awareness training modules would be the most beneficial, followed by 56% who felt an online equivalent would be helpful. 6/10 felt targeted, in-person equalities training session would be beneficial. Around half said they would benefit from online equalities training sessions or written resources.

Even those who considered their services to already be LGBTQ inclusive acknowledge room for improvement

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"I think our service is fairly LGBTQ aware but think more support and guidance should be available generally to support Health care workers in this area"

"I think it would be a good idea to run workshops to improve everyone's ability to capture the information correctly and feel less inhibited to ask such questions."

Whether or not these training sessions were made mandatory would be an important consideration. As one respondent noted, if not, then services would run the risk of only engaging staff who were already engaged.

The need for LGBTQ+ awareness training more broadly was frequently cites throughout the consultation, with some respondents sharing negative experiences of discrimination due to being LGBTQ+ in the workplace. This unfortunately echoed some of the experience shared by LGBTQ+ community members engaged through the survey and focus group, and serves as a reminder for the ongoing need for greater awareness and acceptance of gender and sexual variation.

"I am saddened by the instances of prejudice I have witnessed against someone who has appeared not to present as conforming to their evident sex […] I have personally experienced hostility from fellow colleagues on the mere presumption of my status (as a trans woman) […] I am so saddened by this as I [joined the organisation] to contribute to the greater good of the community of which I am a part."

Summary of findings

A limited understanding and awareness of the value of monitoring

A lack of clarity in healthcare settings about the purpose of collecting monitoring data seemed to feed a general reluctance to monitoring, which came to be seen as "another box ticking exercise", both for services and for patients/ service users. Through the meetings and survey, there was a general sense of confusion regarding whether this information should be recorded anonymously, for statistical purposes only, or whether it should be used for clinical purposes and form part of the patient record.

A recurring theme was that if the information is not perceived as clinically relevant then staff are reluctant to ask. A tendency to rely on 'notes' on system, rather than officially recording the information in a way that can form part of the patient record and be used for statistical purposes. A lack of understanding of the purpose and value of monitoring with service providers is reflected in this lack of clarity with the LGBTQ+ community.

Limited LGBTQ+ awareness and understanding and awareness of LGBTQ+ health inequalities

A low level of understanding of LGBTQ+ health inequalities came through in the meetings with surgeries, and in the survey. That monitoring could be beneficial for understanding LGBTQ+ health inequalities and health needs was not widely understood, and as a result, monitoring was perceived as either only for generic statistical purposes, or only when the information was seen as directly clinically relevant to a patient's presenting issue.

Furthermore, gender and trans status were frequently conflated, and the distinctions between these characteristics were not well understood, reflected in low levels of monitoring around these. Perhaps relatedly, lower levels of confidence and comfort were reported in relation to trans status and gender monitoring, an area in which knowledge and understanding is, though growing and improving, still in its relatively early stages.

The distinctions between 'sex' and 'gender' were also not widely understood, and these terms were often used interchangeably. In addition to resulting in poor quality data, the practice of conflating these terms can present an inclusion barrier for many trans and/or non-binary people, as discussed in the LGBTQ+ community survey and focus group findings.

Further to this, it bears mentioning that intersex status has been a largely neglected area in monitoring thus far, and that the particular needs and experiences of intersex people have not been adequately addressed or captured by this report.

Monitoring is not perceived as a priority

This is fed by a lack of understanding of the purpose and benefit of monitoring to the service and patients/ service users, as discussed above. Time and resource limitations strongly contribute to this, the survey and meetings suggest.

Monitoring SOGITS is perceived as intrusive and inappropriate

Related to the lack of understanding of the benefits and purposes of monitoring, and limited understanding of LGBTQ+ issues and health inequalities, a strong theme of monitoring being considered inappropriate and intrusive came through in the survey comment responses.

IT systems are a key challenge

Issues with IT systems being incompatible with an acceptable range of options for sexual orientation, gender and trans status were a common theme throughout the meetings and survey. Inconsistency between different systems also means that communicating patient information between departments and services can be difficult. Procedures for updating and transferring information from the records of those who have transitioned and been assigned a new NHS number were a key concern.

Sexual orientation, gender and trans status are perceived as 'LGBTQ issues' only

Reluctance and reservations regarding monitoring were also expressed on the basis of sexual orientation, gender and trans status being issues that are only relevant to LGBTQ+ people. There was therefore a view that monitoring these characteristics was only relevant to a minority of patients and may be perceived as giving LGBTQ+ people unfairly special status, alienating or excluding

heterosexual cisgender people. That everyone has a sexual orientation, gender or trans status (including heterosexual cisgender people) and health needs that are relevant to these was not a baseline understanding, revealing a degree of hetero- and cis-sexism in the current approaches to prevalent thinking about monitoring for these characteristics. A lack of understanding of LGBTQ+ health inequalities is also likely to play a part in contributing to a lower valuing of monitoring for these characteristics.

Conclusion

This report highlights a number of areas of challenge in relation to capturing and using monitoring information effectively for sexual orientation, gender and trans status. However, it also points to many of the ways in which these can be addressed through a harmonised approach to data collection, IT system support, awareness-raising training, and increasing LGBTQ inclusivity within services.

The focus group and survey with the community consistently found that LGBTQ people actively wanted to share their information with services they trusted, when they understood the reasons for monitoring. LGBTQ+ people want to be assured of the ways in which monitoring is being used in service of their communities, rather than being 'just another box-ticking exercise', as one focus group participant put it.

Furthermore, it is important to highlight the ways in which trans and non-binary individuals face particular barriers to inclusion in the sexual orientation monitoring practices as recommended by NHS England, and the limits to the meaningfulness of this data when taken in isolation from gender and trans status.

The Inclusion Award, piloted by LGBT HIP in partnership with the Trans Alliance, has already laid solid groundwork in terms of understanding barriers to healthcare access for LGBTQ+ people, and has already developed and implemented a framework for addressing these with services through training, guidance and a range of resources. The Inclusion Award could therefore be an effective mechanism for delivering some of the recommendations made by this report.

The meetings and survey with healthcare providers demonstrated that much of the resistance to monitoring originates in a lack of understanding about the benefits and purposes of monitoring, both operationally and in terms of service user and patient health and wellbeing outcomes, and a lack of guidance, information and resources on how to carry it out well. While there is much work to be done in this area, the survey and meetings with healthcare providers demonstrated a real appetite for further training, information and resources – all of which would address many of the current barriers to effective monitoring.

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