Good practice guide to monitoring sexual orientation and trans status 2021

IF WE'RE NOT COUNTED, WE DON'T COUNT

LGBT foundation

Introduction

In 2017, LGBT Foundation launched a good practice guide to monitoring sexual orientation. This resource provided advice on implementing the newly launched Sexual Orientation Monitoring (SOM) Information Standard. This Information Standard provides the mechanism for recording the sexual orientation of patients and service users across all health services and Local Authority social care providers in England. Since 2017, huge progress has been made and the Information Standard has allowed services across the country to effectively monitor sexual orientation.

However, there is still more work to do when it comes to monitoring. This guide will provide updated guidance, tips and case studies for areas implementing sexual orientation monitoring and has been produced in collaboration with the LGBT Foundation and NHS England. This updated guidance also includes information about trans status monitoring (TSM) and inclusive gender monitoring, as this is an area that providers may need additional support with, in lieu of an Information Standard at present. If services want to improve the care and support provided to lesbian, gay, bisexual and trans (LGBT) communities, it is crucial that they monitor both sexual orientation and trans status. Therefore, this guide aims to help services effectively implement both sexual orientation and trans status monitoring.

We still have a long way to go when it comes to embedding routine sexual orientation and trans status monitoring across the health and social care sector. At the time of writing, sexual orientation is still not being routinely monitored in the majority of services and routine trans status monitoring is even less common. This new guide aims to help push monitoring further up the agenda and highlight the case for its importance. In 2021 monitoring has never been more essential, the COVID-19 pandemic has revealed deep rooted inequalities in this country and has shown that these inequalities can have significant and even deadly consequences. The pandemic has also widened existing inequalities, the consequences of this will still be felt in years to come.

This guide explains how monitoring plays an instrumental role in identifying and addressing inequalities. It aims to provide clear and practical guidance to any service that wants to implement effective monitoring. It also explains how monitoring is not a stand-alone step, it is only useful if the findings are used to better support LGBT patients and to underpin strategies to address LGBT health inequalities. This guide explains how to use the information collected through monitoring to improve services for LGBT people.

Contents

1. What is sexual orientation and trans status monitoring?

Put simply, sexual orientation and trans status monitoring is asking people accessing health and social care services about their sexual orientation, trans status and gender identity and recording this information.

Before reading more about sexual orientation, trans status, and gender identity monitoring it is important to understand what these terms mean. For a full glossary of terms see Stonewall's glossary www.stonewall.org.uk/help-advice/faqs-and-glossary/glossary-terms.

Sexual orientation describes who an individual is emotionally and sexually attracted to. Some of the most common orientations are heterosexual or straight, lesbian, gay, and bisexual, but these are by no means exclusive. For example, some people may identify themselves as queer, asexual or pansexual.

Trans status is whether or not someone is trans. Some people may refer to this as 'trans history'. Trans is an umbrella term to refer to individuals whose gender identity doesn't completely match the sex they were given at birth. This includes trans women, trans men, and non-binary people. However, it is important to recognise that some non-binary people do not identify as trans. Trans people are protected under the Equality Act (2010) under the protected characteristic of 'gender reassignment'. To be protected from gender reassignment discrimination, an individual does not need to have undergone any specific treatment or surgery. This is because changing physiological or other gender attributes is a personal process rather than a medical one.

Cisgender or cis refers to someone whose gender identity is the same as the sex they were assigned at birth. Non trans is used by some people.

Gender identity A person's innate sense of their own gender, whether male, female, non-binary or something else, which may or may not correspond to the sex assigned at birth. It is important to note that gender identity and sexual orientation are separate things.

Gender identity and trans status are often used interchangeably, but they mean different things. Gender identity refers to someone's gender, such as male, female, non-binary. Trans status refers to whether someone's gender identity is the same as the sex they were given at birth. Trans is not a gender identity, a trans woman's gender identity is female and a trans man's gender identity is male. Trans is an adjective and should be used in the same way as you would use any other adjective such as a funny woman, a tall man, a clever person.

2. How to ask about sexual orientation

When monitoring sexual orientation, it is important to ask questions in the right way so that communities understand how to answer in a way that ensures accurate and robust data is collected. When done appropriately, monitoring can demonstrate that services are culturally competent and can help LGBT people feel included by a service.

Sexual orientation should be monitored in line with the questions on the Sexual Orientation Monitoring Information Standard.

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

Non-responses/ not know are coded as follows:

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)

2.1 The Sexual Orientation Monitoring Information Standard

The Information Standard for sexual orientation monitoring (SCCI2094) was published in October 2017 by NHS Digital and NHS England. An Information Standard is a document used across the health and social care system to help collect and process information in a consistent way.

The Information Standard was commissioned by NHS England and developed by LGBT Foundation working with NHS Digital, the Department of Health, Public Health England and a cross-system group with representation from leaders across health and social care as well as organisations representing the workforce.

This Information Standard provides the mechanism for recording the sexual orientation of all patients and service users aged 16 years and over. It is applicable across all health services and Local Authorities with responsibilities for adult social care in England. However, the Standard can be used as good practice in organisations from all sectors and for all age groups, demonstrating a commitment to appropriately and comprehensively monitor the sexual orientation of staff and service users. To read the Sexual Orientation Monitoring Standard full specification www.england.nhs.uk/publication/sexual-orientation-monitoring-full-specification.

The Information Standards development team consulted with the national SNOMED CT team and the NHS Data Model & Dictionary Service at NHS Digital to ensure that SNOMED CT codes are compatible with the question set for this Standard. SNOMED CT https://digital.nhs.uk/services/terminology-and-classifications/snomed-ct is a structured clinical vocabulary for use in an electronic health record, it gives clinical IT systems a single shared language. All NHS healthcare providers in England must now use SNOMED CT for capturing clinical terms within electronic patient record systems.

> **Sexual orientation and trans status monitoring should be a key part of any work undertaken to address inequalities in health and social care.**

2.2 Recording categories

In settings and circumstances where dataset owners and health and social care organisations record patient or service user sexual orientation, the data should be recorded as follows:

Classification Number	Classification Narrative	Description
1	**Heterosexual or straight**	Classifications 1-3 are those which people are most likely to be familiar with, and are intended to simplify the question and answer.
2	**Gay or lesbian**	Classifications 1-3 are those which people are most likely to be familiar with, and are intended to simplify the question and answer. Classification 2 is 'gay or lesbian' as this category will include some women who identify as gay rather than lesbian. Analysts will need to cross-tabulate gender with sexual orientation in order to understand the different responses of different groups within LGB.
3	**Bisexual**	Classifications 1-3 are those which people are most likely to be familiar with, and are intended to simplify the question and answer. Analysts will need to cross-tabulate gender with sexual orientation in order to understand the different responses of different groups within LGB.
4	**Other sexual orientation not listed**	Classification 4 allows the individual to identify as other than heterosexual/straight, lesbian, gay or bisexual, including but not limited to asexual or queer (estimated to be a small minority of non-heterosexuals). Where it is feasible to collect and analyse free-text data, organisations should include an option here allowing respondents to identify their own sexual orientation.
U	**Person asked and does not know or is not sure**	Classification U allows recording where an individual does not know or is not sure, consistent with terminology in the Data Dictionary used by the health and social care system.
Z	**Not stated** *(person asked but declined to provide a response)*	Classification Z allows the individual not to disclose this information, as is their right.
9	**Not known** *(not recorded)*	Classification 9 is not intended to be visible to the patient or healthcare professional but is needed to account for missing data in analysis, i.e. where there is no record of sexual orientation. Categories U, Z and 9 are designed to record different data, and should not be merged as one 'non-response' category.

The categories used in the standard have been worded to better encompass sexual orientation, sexual attraction and sexual behaviour, and to reinforce the fact that sexual orientation is about identity rather than sexual partners.

Sexual orientation is always a matter of self-identification and self-disclosure. In situations where this would not be possible, (e.g. patients requiring care under the Mental Capacity Act, where they are not able to give consent and therefore would not be able to declare their sexual orientation), only classification 9 could be recorded. System suppliers and organisations implementing this standard must ensure that they update their clinical safety case reports and their privacy impact assessments to accept any potential impact and set out steps to manage it. The Information Commissioner's Office can advise on privacy impact assessment. To find out more visit https://ico.org.uk.

2.3 Compatibility with IT systems

IT system suppliers have confirmed that the above categories are compatible with the products they provide to health and social care organisations. It should be noted that the SNOMED system which holds electronic medical records cannot accurately record all individual sexual orientations. For those who select option 4, 'other sexual orientation not listed', the SNOMED concept ID 765288000 ('sexually attracted to neither male nor female sex') can be used to record people who write in 'asexual'. For people who write in terms such as 'queer' or 'pansexual', there is not an accurately matching code in SNOMED. For this reason, we would advise that where respondents use multiple terms to describe themselves, the terms that best fit into SNOMED coding should be used. However, this will not always be possible as some people will not feel that any of the sexual orientations listed will describe them accurately. In this instance where there is not an appropriate SNOMED code, and where consent is given, it is best to put a note on their record outlining how they identify, as would be done with trans status monitoring.

2.4 Implementation

Implementation Guidance on the Information Standard can be found on NHS England's website https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/dcb2094-sexual-orientation-monitoring.

Organisations implementing the standard should record sexual orientation data using the same recording and reporting method for other equalities data such as age and gender. We recommend that organisations should take a phased approach to implementation and make any necessary changes to IT systems as part of broader system updates, therefore reducing the costs of implementation. Advice on overcoming barriers when implementing monitoring and guidance around analysing and using the data collected can be found in sections 6, 7 and 8 respectively.

3. How to ask about gender identity and trans status

As with sexual orientation, it is very important that questions on gender identity and trans status are asked in the correct way. Our recommended question and answer format for monitoring trans status has been agreed as best practice by LGBT Foundation, CliniQ and Action for Trans Health with input from trans communities and the National LGB&T Partnership. These questions are in line with the HIV and AIDS Reporting System (HARS) questions on trans status and gender identity, for more information about the HARS question see https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/816919/GUMCAD_STI_Surveillance_System-Clinical_guidance_July-2019.pdf

Gender identity and trans status should be asked as a two- step question as follows:

Question one: gender identity

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

1. Woman [including trans woman]
2. Man [including trans man]
3. Non-binary
4. In another way

The followings codes can be used for non-responses:

Z. Not stated (PERSON asked but declined to provide a response)
X. Not known (not recorded)

Question two: trans status

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

1. Yes
2. No

The followings codes can be used for non-responses:

Z. Not stated (PERSON asked but declined to provide a response)
X. Not known (not recorded)

There is currently no national trans status monitoring information standard, although there is ongoing work to develop a standardised approach and to update IT systems so that trans status can be properly recorded. However, this should not hold services back, there are ways to effectively monitor without an information standard.

Trans status monitoring is becoming more prominent and LGBT organisations such as LGBT Foundation and Brighton and Hove Switchboard have supported services to implement trans status monitoring effectively.

Services which have implemented trans status monitoring usually gain consent from the individual to place a note on their medical record to say that they are trans and/ or to say that their gender identity is something other than male or female.

Services should ensure that this information is informing the care they are providing. For example, services should note that patients documented as male on their medical record will not routinely receive invitations for cervical screening. Services should therefore be aware of any patients who are trans men or non-binary people assigned female at birth and proactively ensure that anyone with a cervix is receiving invites for cervical screening.

Services should also analyse data they have on trans and non-binary patients to improve their knowledge of the experiences and needs of these patients and identify any inequalities that need to be addressed. More information about how monitoring can be used to improve services can be found later in the guide.

4. Understanding why monitoring is necessary: LGBT health inequalities in the UK

Services should be taking proactive steps to improve care for LGBT communities who face a range of health inequalities throughout their lives, which are further compounded by inequalities when accessing health and social care. Monitoring enables the health and social care sector to better understand LGBT inequalities and recognise the ways in which their services need to be improved to address these inequalities.

Findings related to LGBT health inequalities include:

- A 2018 report from Stonewall found that 48% of LGBT people aged 18-24 said they'd deliberately harmed themselves in the last year. 35% of trans people had self-harmed in the previous year, compared to 14 per cent of LGB people who aren't trans. More than one in four LGBT disabled people (28 per cent) have self-harmed compared to 11 per cent of LGBT people who aren't disabled. According to research for NHS Digital, around six per cent of adults in general said they had self-harmed in the last year[1]
- The 2019 NHS GP Patient Survey found that 6% of bisexual respondents and 4.9% of gay and lesbian respondents were living with frailty, compared to 3.2% of all respondents.
- A 2020 evidence review found that among men aged 50+, being gay, bisexual, or another non-heterosexual orientation is associated with a heightened risk of long-term illness and health-related limitations.[2]
- Office for National Statistics (ONS) figures show that 18.8% of heterosexual people smoke, compared to 27.9% of lesbian women, 30.5% of bisexual women, 23.2% of gay men and 26.1% of bisexual men.[3] The evidence that exists on smoking rates in trans communities suggest that they are also more likely to smoke compared to the general population.[4]
- The Queerantine Covid-19 Study found that 69% of LGBT respondents suffered depressive symptoms, rising to about 90% of those who had experienced homophobia or transphobia. Trans and gender diverse people had the highest scores for perceived social or depressive symptoms.[5]

LGBT people face a number of inequalities when accessing health and social care, which can make people reluctant and even unable to access healthcare, for example:

- A 2018 Stonewall survey found that 14% of LGBT people have avoided accessing healthcare for fear of being discriminated against because of their LGBT identity.[6]
- A 2017 LGBT Foundation Primary Care survey found that 33% of LGBT respondents thought that their GP did not meet their needs as an LGBT person and 72% said they thought GP practices could improve services they offer their LGBT patients.[7]
- A 2016 review by the Race Equality Foundation found that black, Asian and minority ethnic trans and non-binary people face 'extreme barriers in accessing physical and behaviour health care.' Part of this is due to prevalent transphobia and racism when accessing healthcare.[8]
- A 2017 LGBT Foundation survey found that 80% of trans people experience anxiety before accessing hospital treatment due to fears of insensitivity, misgendering and discrimination.[9]
- The National LGBT Survey 2018 found that 13% of cis LGB people who had accessed healthcare services in the previous 12 months had had a negative experience due to their sexual orientation. This figure rises sharply to 40% of trans people who had a negative experience based on their trans identity. Additionally, 19% of trans people felt their specific needs were ignored or not taken into account.[10]

For a comprehensive report on LGBT health inequalities in the UK see LGBT Foundation's Hidden Figures report here https://lgbt.foundation/hiddenfigures. To view LGBT Foundation's research on LGBT inequalities and COVID-19 see here https://lgbt.foundation/coronavirus/hiddenfigures.

This research clearly demonstrates that more needs to be done to address LGBT health inequalities and inequalities in access to care. Monitoring should be a key part of any work undertaken to address inequalities in health and social care. Monitoring helps to improve the care provided to LGBT people, improve knowledge of the experiences of LGBT communities and shape policies to address inequalities. The next section outlines the numerous benefits of monitoring and explains how monitoring is instrumental within work to address LGBT health inequalities.


“Services should be taking proactive steps to improve care for LGBT people who experience a range of health inequalities throughout their lives.”

5. How monitoring can improve services and help to address health inequalities

5.1 Improving patient care

Understanding a patient's background and current needs will help practitioners to improve the level of person-centred care they can provide. The 2017 LGBT Foundation Primary Care Survey found that LGBT people who shared their sexual orientation with their GP were 21.4% more likely to feel their GP met their health needs as an LGBT person, compared to patients who did not disclose.[11]

A person's sexual orientation and trans status make up an important part of a their identity. Having this information can help the service provider better tailor care to the individual so that high quality personalised care can be achieved. LGBT people may have different needs and experiences compared to heterosexual cisgender people and the care they receive should reflect this. Two LGBT community members explain how their LGBT identity was taken into account when receiving care:

> *'When it came to my smear test, they made an effort to find the smallest speculum available and said it would be most comfortable because of the type of sex I had. It was amazing that I felt the healthcare I received was specific to my lesbian identity.'*

> *'Know that disclosing trans status will lead to an opportunity to be connected to the right health & screening services despite being registered as 'male' i.e smears and mammogram if needed.'*

Monitoring can help services to address inequalities that their LGBT service users may be facing. If a service is aware of a person's LGBT identity, they will be able to have conversations about issues that they know may be more likely to affect that person. Cervical screening uptake is lower among LB women, with some thinking that LB women do not need to access cervical screening[12], therefore a healthcare provider may wish to explain to lesbian and bisexual (LB) female patients that they should be attending cervical screening. A community member gives another example of this:

> *'I proactively disclosed my sexual orientation as it was relevant. The GP took it into consideration for the issues I presented - fertility as a lesbian couple and was supportive.'*

Monitoring helps to improve patient care by providing an opportunity for services to carry out targeted and personalised signposting and social prescribing. LGBT patients may benefit from the support of an LGBT specific organisation, however if their LGBT identity is not known then services will not know to signpost to LGBT specific support. For example, a non-binary person may present to their GP with concerns around substance misuse, but they may not feel comfortable accessing mainstream peer support for substance misuse as they are worried about facing discrimination and being misgendered. They may instead benefit from an LGBT substance misuse support group where they feel safe and comfortable. If the GP did not know that this person was non-binary, they would not know to discuss this option with the individual.

Monitoring can make LGBT patients feel as if their identity has been recognised and taken into consideration. This is important as LGBT people often feel as if their identity and specific needs are not acknowledged when accessing services. The inclusion of monitoring questions on registration forms can be a good first sign that a service is LGBT inclusive.

> *'If there was a specific question about trans status on the registration form it would help make me feel that my gender is recognised formally and not to have to hope for the acceptance of an individual GP or dentist etc.'*

For LGBT people coming out can be very stressful, especially when worrying about whether there is an appropriate and safe time to do so. Monitoring provides an opportunity for the individual to record their sexual orientation and trans status if they wish to. This can enable the individual to raise issues relating to their sexual orientation and trans status. If someone's sexual orientation and trans status has been recorded, then they will no longer have to continually come out when accessing services.

> *'My partner and I attend the same GP and have done for over 10 years. They still don't recognise she is my partner and ask about my husband. It would encourage me to share my sexual orientation on a monitoring form if there was an IT system that links up data and talks to other NHS systems so I don't have to keep 'coming out"*

5.2 Business case

Monitoring allows services to more efficiently direct and allocate services to where there is greatest need. Health and social care interventions, campaigns and strategies can be better targeted to the appropriate individuals.

For example, monitoring sexual orientation in sexual health services has shown that men who have sex with men are disproportionately more likely to be affected by various STIs. Being aware of this inequality allows local authorities to commission specific, targeted services to meet this need for men who have sex with men.

Recording sexual orientation and trans status across health and social care will enable policy makers, commissioners and providers to better identify health risks at a population level. This will support targeted preventative and early intervention work to address health inequalities, which is shown to reduce expenditure linked to treatment costs further down the line.

Comprehensive monitoring means health and social care organisations will be able to demonstrate the provision of equitable access for LGBT individuals and support them to be compliant with the Equality Act 2010. It will contribute to the improvement of care providers' understanding of inequalities in health and care outcomes for different populations. Monitoring the sexual orientation and trans status of staff members will help to demonstrate that the organisation recognises the importance of addressing and reducing inequalities for LGBT staff. It shows an organisation's investment in the workforce and can lead to increased employee retention. Successful monitoring has shown that LGBT people are more likely to experience discrimination and harassment at work and are less likely to report it when it occurs. For example, the 2018 NHS Staff Survey found that 20.7% of LGB staff had experienced discrimination in the preceding 12 months, compared to 11.9% of heterosexual staff. Collecting this information will allow organisations to take steps to address such inequalities.

5.3 Policy context

It is a legal requirement for public organisations to consider how they treat all people fairly and equally. The Equality Act 2010 created the Public Sector Equality Duty which covers the protected characteristics: age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex, and sexual orientation. Public authorities need to have due regard to these characteristics, as well as the need to eliminate unlawful discrimination against someone because of their marriage or civil partnership status.

Monitoring for protected characteristics, including sexual orientation and trans status (defined as gender reassignment in the Equality Act), can play an important role in helping organisations to demonstrate that they are complying with the Duty.

The key requirements of the public sector Equality Duty are to:

- eliminate discrimination, harassment and victimisation;
- tackle prejudice and promote understanding;
- advance equality of opportunity;
- remove or minimise disadvantages that are connected to a particular characteristic;
- take steps to meet the needs of people who share a protected characteristic, based on real life experience and evidence of need.

The NHS Constitution states that, *"the NHS provides a comprehensive service, available to all irrespective of gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status."* Monitoring will help to ensure that NHS services can demonstrate that they are providing this service.

The Equality Delivery System (EDS2) for the NHS further supports monitoring through its outcomes covering patient care, access and experience. NHS providers can analyse performance against these outcomes for each group afforded protection under the Equality Act 2010.

The Equality Framework for Local Government comprises five performance areas for addressing equality for both staff and service users:

- Knowing your communities
- Leadership, partnership and organisational commitment
- Involving your communities
- Responsive services and customer care
- A skilled and committed workforce.

Monitoring will ensure that local authorities can demonstrate that they are performing against each area. In addition to this, many organisations will have a commitment to equality of access and opportunity in their existing policies, and monitoring will ensure that these commitments are fulfilled.

The EDS2 framework can help NHS organisations deliver on the Public Sector Equality Duty and is mandatory in the NHS Standard Contract. Monitoring sexual orientation and trans status can help organisations to progress EDS2 outcomes and better understand the needs of LGBT communities.

Quality Accounts are published every year by each NHS healthcare provider and detail the quality of services. Progress on monitoring sexual orientation and trans status can be an integral part of a service's Quality Account. Quality Accounts advisory guidance recognises good quality information underpins effective patient care and that improving equality data will improve patient care and value for money. It also suggests that data in the reports should be disaggregated for equality groups, and monitoring sexual orientation enables this to be done for LGBT groups.

A key ambition in the 2019 NHS Long Term Plan is to make personalised care 'business as usual' across the NHS. The subsequent 2019 NHS action plan Universal Personalised Care: Implementing the Comprehensive Model recognises that personalised care contributes towards reducing health inequalities.[13] Therefore, in order to both meet the ambitions in the NHS Long-Term Plan and to reduce LGBT health inequalities, NHS services should prioritise ensuring health and care services are consistently providing high quality personalised care to LGBT communities. Monitoring is a key element of personalised care and not knowing someone's trans status and gender identity can limit the level of personalised care that can be provided to LGBT communities.

5.4 Improving the evidence base

There are still gaps in the evidence on the experiences of LGBT communities, this lack of data means we do not have a full picture of LGBT health inequalities in the UK. For example, there is no evidence on the infection rates of COVID-19 in LGBT communities and due to a lack of routine sexual orientation and trans status monitoring it is likely that we will never know the number of LGBT people who were admitted to hospital and/or died from COVID-19. There is a specific lack of data on intersectional inequalities groups within LGBT communities, such as LGBT People of Colour and older LGBT people. A 2016 review by the Race Equality Foundation found that a lack of research on the experiences of black Asian and minority ethnic trans and non-binary people means that we do not fully know the extent of the inequalities experienced by these communities.[14] Additionally a 2020 review of the health of LGB (lesbian, gay and bisexual) older women, concluded that is 'one of the of the most neglected research areas in UK gerontology' (gerontology is the study of the aging process and the problems that older people might encounter).[15]

This lack of evidence means that there are LGBT health inequalities that are not being properly recognised, and issues that are not recognised will go unaddressed. Lack of data and research also means that some health inequalities that have been recognised are still not fully understood, which limits how effective any interventions can be.

Lack of evidence makes it harder to create a strong case for commissioners and funders to support work to address LGBT health inequalities. This creates a vicious circle where lack of monitoring means there is not sufficient evidence to show that LGBT health inequalities exist, which means that there is not proper funding to address these issues. This means that sufficient support is not given to monitoring, which in turn means the evidence based does not expand, and so on.

Lack of data also makes it harder to measure the impact of work to address LGBT health inequalities. For example, the rate of smoking in trans and non-binary communities is not known, so it would be harder to measure the impact of a programme that aims to reduce smoking in these communities. However, if research, such as the ONS data on adult smoking habits in the UK, collected information on trans status we would be able to see any changes in smoking habits in trans communities.

6. How to overcome barriers when implementing monitoring

Despite the fact that someone's LGBT identity may be relevant to their care, professionals often do not ask for this information. This is often due to misconceptions that it is not relevant, as well as fears of causing offence and a lack of confidence around how and what to ask. A Stonewall survey of health and social care professionals found that 57% said they did not think sexual orientation was relevant to people's health needs.[16]

While many LGBT people would not mind if a healthcare professional asked about their sexual orientation and trans status, some LGBT people may be reluctant to disclose this information. This could be because they don't feel comfortable, they don't feel that the information is relevant to their care at that moment, or they don't understand what the information collected during monitoring will be used for.

The Government's National LGBT Survey in 2018 found that, of those who were not open about their sexual orientation when accessing healthcare, 83% gave 'it was not relevant' as a reason, 14% said 'I was afraid of a negative reaction' and 14% said 'I did not want to reveal my sexual orientation'.[17] A 2018 evidence review found that barriers to disclosing LGB identity in a healthcare setting were widespread. The most significant factors that determined whether someone would disclose their sexual orientation were people feeling like their sexual orientation was not relevant to the care they were receiving and fears of poor or unequal treatment as a result of disclosure. The communication skills and language used by the healthcare professional were also very important, with heteronormative language and unfriendly body language making people less likely to disclose.[18]

There are a number of steps that are important to take to make service users feel more comfortable to disclose their LGBT identity and to help staff to feel more comfortable and willing to ask questions:

Understand and communicate the importance and purpose of monitoring people's sexual orientation and trans status and use this information to improve and personalise care. If services can demonstrate how asking these questions is improving the care they provide it can make people more willing to disclose. An LGBT Foundation patient survey found that 78% of LGB people and 65% of trans people who would not currently disclose their LGBT identity said they would be encouraged to do so if they saw monitoring being used to improve services.[19]

> *'Knowing general practice recognizes the different needs from the LGBT community would encourage me to share my sexual orientation.'*
>
> *'Feeling like medical professionals such as GPs are trained in how to care for trans people, feeling understood and feeling like the person genuinely cares and understands me and puts me at ease would encourage me to share my sexual orientation.'*

Have a **confidentiality policy** that is easily accessible and well understood by everyone involved in the process. Service users need to understand what is going to happen to their data, how it will be used and with whom it may be shared. Confidentiality policies should also state why this information is being collected and why it may need to be shared. Confidence in confidentiality will ensure confidence in your organisation and increase disclosure rates.

> *'Confidence that it will stay confidential unless there is concern regarding my birth gender would encourage me to share my trans status.'*

Create a space for open and judgement free communication so that people feel comfortable to share personal information. Do not act surprised when people share personal information and make a conscious effort to be non-judgmental and supportive. Continue this practice and stay open to further communication as people's needs and identities may change over time.

An LGBT community member explains how language and communication can make them more willing to disclose their LGBT identity:

> *'Staff using language that is open, having an informed and welcoming approach and manner, supporting any signaling/monitoring questions that are in place. Sometimes places are good on paper but the staff team themselves do not actually understand LGBT identities e.g. misgender me.'*

Do not make assumptions, you won't know how someone identifies just by looking at them. Always ask rather than assume. Making assumptions about a person's gender, the gender of their partner, or how they identify can make people feel as is their identity is invisible. This may mean that some people feel less comfortable disclosing their LGBT identity.

> *'My partner and I attend the same GP and have done for over 10 years. They still don't recognise she is my partner and ask about my husband.'*

Ask about sexual orientation and trans status routinely. Most service providers do not think twice when asking routine questions about things such as age, ethnicity and disability, and asking questions about sexual orientation and trans status should also be routine. Do not shy away from asking these questions, they should not be something that is embarrassing to talk about.

> *'It would encourage me to share my sexual orientation if people didn't sound/ look apologetic or make excuses while asking you the question! i.e. they shouldn't say 'I'm sorry but I have to ask you this... or look uncomfortable while asking - I've had this so many times and the effect is to make me feel I don't want to answer truthfully, although I do persist, I won't feel comfortable or respected myself.'*

Improve visibility to improve the environment for LGBT people. Simple steps such as wearing rainbow lanyards or rainbow badges, putting up posters of LGBT organisations and having visible inclusion policies can help LGBT people feel more comfortable to disclose their LGBT identity. The 2018 LGBT Foundation Pride in Practice Patient Survey also found that where services displayed LGBT posters LGB patients were 24% more likely to share their sexual orientation with healthcare professionals, and trans patients were 21% more likely to share their trans status.[20]

> *'Seeing action being taken publicly when discrimination takes place and seeing the practice making a visual effort to show it is inclusive and supportive would encourage me to me to disclose my sexual orientation.'*

> *'Staff wearing badges stating names and pronouns to show trans inclusion would encourage me to disclose my trans status.'*

LGBT inclusion and awareness training is instrumental in helping services to carry out the above steps. It is important that staff training is provided before implementing monitoring to ensure that staff are confident and comfortable in discussing sexual orientation and trans status. Training needs within organisations should be identified based on people's role in monitoring. All staff can benefit from general LGBT awareness training, and staff who will be working with service users will likely need specific training on why and how to monitor protected characteristics. This might also need to include guidance on how to record sexual orientation on each specific IT system in use.

LGBT Foundation's Pride in Practice Training Academy has a range of modules on LGBT inclusion and awareness, including one on monitoring sexual orientation and trans status, see https://lgbt.foundation/trainingacademy for more information.

“My partner and I attend the same GP and have done for over 10 years. They still don’t recognise she is my partner and ask about my husband. It would encourage me to share my sexual orientation on a monitoring form if there was an IT system that links up data and talks to other NHS systems so I don’t have to keep ‘coming out”

7. Analysis of monitoring data

Analysing your data is about much more than just counting your service users or staff. Break it down to look at:

- who is using your services and how?
- what is the makeup of your workforce across levels and grades?
- what is the experience of both staff and service users?

The following points are some important ways that data collected through monitoring can be analysed. For all of the suggestions below, make sure that any analysis maintains confidentiality, for example, by anonymising data.

- The LGBT community is often considered as a homogenous group but monitoring across sexual orientation and trans status allows you to break it down into its component parts. A lesbian woman will likely have different experiences and needs to a bisexual non-binary person. Identifying these differences in experience can help to better target support and improve service user outcomes.
- Carry out intersectional analysis and analyse data across all protected characteristics: identify where there are gaps, trends and differences and compare data across equality groups. People will identify across a range of characteristics; there will be differences when comparing the experiences of a young, black, bisexual woman to an older, white, lesbian woman. Identifying these differences in experience can help to better target support and improve service user outcomes.
- Service user data can be analysed to see who is using an organisation's services and how. It will also show who services are not engaging with. Data collected through monitoring should be compared with data available on the area's wider population to discover potential differences, and target work to improve equality of access. The 2021 England and Wales Census asked questions about sexual orientation and gender identity for the first time. The census results will provide a clearer a picture of the make-up and size of LGBT communities across the country, allowing services to cross-reference and compare their service user data with census data. This will help services to identify any communities that they may not be reaching and help to create a case for implementing targeted support.
- To make it easier to compare data with other datasets, services could design their collection methods in collaboration with a partner organisation or authority (for example, a local council).

- Services should find a critical friend in specialist service providers (such as an LGBT organisation) to review monitoring data and feed into the analysis. Getting an outside perspective is essential in ensuring nothing is missed when carrying out analysis.
- Services should make year-on-year comparisons with the data they are collecting, looking at what has changed in responses and disclosure rates. If there are changes, services should think about might be causing these. Similarly, if data has remained fairly static, services should think about why this is. It is important to look for gaps in the data that has been collected and develop targets to improve data quality.

Analysing monitoring data provides important information which will enable services to highlight and address inequalities. Good preparation and collection methods should increase rates of completion and disclosure. However, if the returns are initially low, services can address this by evaluating and improving their methods. Engaging with staff and service users about their experiences of monitoring is vital; for example, staff may require additional training or support around effectively asking monitoring questions and service users may need further reassurances about how their data will be used.

8. Effective use of monitoring data

It is important to remember that monitoring is not an end in itself, but an integral process in ensuring equality. Monitoring is only useful if this data is proactively used to improve services.

Once data on sexual orientation and trans status has been collected it can be used in a number of ways. Section 5 outlined the benefits monitoring can have: it can be used to improve patient care, to implement care that is better value for money, to ensure compliance with equality policies and to fill gaps in the evidence base. The following tips will help you to best use data collected through monitoring and ensure that the data is used to improve the care you provide to LGBT communities and help to combat LGBT heath inequalities:

- Develop targets and objectives from your analysis and use these to improve service delivery (for example, designing targeted interventions).
- Use the data as evidence in commissioning and planning services for specific groups.
- Assess all proposed work programmes and interventions for their potential impact on equality. Use monitoring data as a basis and engage with groups which might be affected by your organisation's decisions.
- If your analysis identifies training needs such as understanding monitoring, challenging discrimination or promoting equality, plan targeted training initiatives and leadership programmes to address these issues.
- Share the headline data (where appropriate) with staff and service users to include them in the monitoring process and encourage them to feel ownership. Celebrating examples of 'you said, we did' will reinforce positive messages about monitoring and increase positive outcomes. If you're going to publish data externally, make sure there's a context for it and a clear purpose for doing so. Releasing data without contextual background or any accompanying analysis to guide readers, and failing to explain how you are acting on the data, will limit both its impact and the ability for others to learn from what you've done. Caution is needed if you're generating a very small amount of data in fields such as sexual orientation and trans status, as it's unlikely to be representative of the population and might even breach confidentiality – for example, reporting that a small department included two LGBT people could put their privacy at risk. Confidentiality protections should be paramount when publishing statistics.
- Develop a virtuous circle – collecting anecdotes of service improvement will feed back into emphasising why monitoring is important.
- Publish the results of monitoring alongside actions that you plan to take in response. Make it clear to people that monitoring is a process to lead to improved outcomes.
- The monitoring process can be used to gather evidence about how your organisation is an inclusive and diverse workplace and/or service provider. Working with an LGBT staff group on changes to organisational policy on parental leave, for example, demonstrates LGBT inclusivity that is supported by monitoring.
- Share your learning and any organisational improvements you have made as a result of sexual orientation and trans status monitoring with colleagues, with partner organisations, and your networks in the field. Sharing success stories across organisations will help embed monitoring as an essential process on the road towards equality.
- Explore opportunities to share data with other services to better understand and meet service users' needs. You will need to consider how data protection and confidentiality can be maintained.
- If your monitoring generates low figures, try to identify why this might be and launch initiatives to increase response and disclosure rates.
- Track your progress with monitoring year on year. Recognise that monitoring is a long term process; introducing it may bring up other issues among the workforce or in service provision that need consideration.

9. Case studies of effective monitoring in healthcare

There is a range of great practice in sexual orientation and trans status monitoring that is happening across the country. Services have been able to effectively implement monitoring and use it to improve the services they provide to LGBT people and improve their understanding of the needs of their LGBT patients. The following case studies are a few examples that provide helpful insight.

Services that are looking to start implementing monitoring should talk to similar services that are already carrying this out and get advice about the implementation process, what services learnt from it, and how they overcame any challenges.

Langworthy Medical Practice

Langworthy Medical Practice collects information about sexual orientation and trans status within their New Patient Health Check (NPHC) form which is then recorded on their IT system.

The service has seen how monitoring can improve their services. They explained how:

> *'It allows our clinicians to be aware of health inequities when seeing LGBT people. Also, all our new trans patients are contacted and asked about their preferred pronouns which is documented in the patient's record. This makes sure they are addressed correctly.'*

They have faced challenges when implementing trans status monitoring in regard to the limitations of the IT system and recalling trans patients for screening. NHS IT systems allow people to change their recorded gender, however they do not currently allow recording of trans status. For example, if a trans man re-registers as a male, he receives a new NHS number and will no longer be automatically called by the NHS call and recall system for cervical screening. To overcome this, the practice keeps a spreadsheet of all their trans patients to ensure they are recalled for appropriate screening. As IT systems develop to better enable the collection on trans status this will, eventually, become unnecessary

Monitoring should not be a standalone step and it is important that services take additional steps to make their services more LGBT inclusive. Langworthy Medical Practice has carried out a range of actions to create a more inclusive environment for their LGBT patients. These have included:

1. Staff wearing Rainbow NHS lanyards
2. Displaying LGBT posters in the waiting room
3. Having a section on their website with information for LGBTQ people
4. Having unisex toilets
5. Removing questions about gender and title on their self-check in screens: if a patient wants to check in, they need their date of birth or first/second name only
6. When a GP calls in the patient only the name of the patient is now displayed on the overhead call screen in the waiting room and not title.
7. Some GPs have completed the LGBTQ+ Health Hub https://elearning.rcgp.org.uk/mod/page/view.php?id=9380, which is a collection of eLearning modules by the Royal College of General Practitioners.

CliniQ

ClinQ is a holistic sexual health, mental health and wellbeing service for all trans and non-binary people, partners and friends. As the service is specifically for trans and non-binary people inclusive monitoring has always been a key priority for them.

The service uses its own form for all people accessing services. This form includes questions on trans status and sexual orientation. The questions on trans status are similar to questions on the HARS monitoring forms but they also include a write in box for people who identify outside of the options given.

There are challenges with uploading this onto the system as write in responses cannot be coded onto the system. However, CliniQ overcomes this by adding a note onto people's record stating how they prefer to identify. Making this small extra effort can mean a lot to someone who has likely never, or rarely, had their identity recognised by clinicians.

CliniQ has found that there are challenges to collection as some people still don't want to disclose their identity. People are unsure how the data will be used and what will happen to it. To help to overcome this CliniQ make sure that they reassure the people accessing their services that they have strong data protection principles, which helps people to feel comfortable to share their data. CliniQ makes sure they get consent to share personal information with relevant people.

CliniQ has found that it is useful to collect this data to help identify LGBT health inequalities, they emphasised that LGBT health inequalities go beyond just sexual health. For example, collecting data through the HARS data set has improved data not just on HIV in LGBT communities but also on a range of other health inequalities and experiences.

The General Medical Council

The GMC is the independent regulator for doctors in the UK. They work to protect patient safety and improve medical education and practice across the UK.

The GMC maintains the register for doctors and sexual orientation was added to this register in 2016. This category was added later than some of the other categories, which means there is less data for sexual orientation than for the categories age, gender and ethnicity. To improve their data on sexual orientation, the GMC ran a campaign in 2019 which highlighted the importance of data collection on characteristics such as sexual orientation for helping to identify and address any issues with inequality and lack of diversity.

They have seen continual improvements in the data collected as it is now a mandatory requirement for all new registrants. They have also established an automated reminder on the GMC online account that pops up when people log on and reminds doctors to fill these fields in on their record. The dataset is now complete enough to allow for some forms of analysis and they have developed and consulted on a format to publish this data (at summary level) on their data explorer tool on registration data, to be launched in 2021.

In relation to patients and others who come into contact with their services, they are planning an equality, diversity and inclusion data review in 2021. This will include reviewing their data collection processes, data quality, and how they use, report, publish and talk about this data.

Simply One Dental

Simply One Dental monitor sexual orientation on their patient registration forms. They have found that the vast majority of people declare their sexual orientation.

Sexual orientation monitoring has helped them to improve the service they provide, they explain that, as a result of monitoring

> *'we are more aware that we can't always assume people's sexual orientation and also what advice and treatments can relate to a person's sexual orientation.'*

They have also found that when someone declares their sexual orientation it can break down barriers and instigate conversations.

They did not face any significant barriers when they added a question on sexual orientation to their forms. There were a couple of negative comments, but aside from that there were no issues.

Simply One Dental say that their team is open-minded and aims to be approachable for everyone, they make sure they support people of any identity and do not judge anyone based on their identity.

Sussex Partnership Trust- Langley Green Hospital

Staff at Langley Green Hospital received LGBT inclusion and awareness training from Brighton Switchboard. This training was instrumental in helping them to imbed monitoring in their services.

They found that monitoring was directly able to improve patient care. They always ask people for their gender and what pronouns they use rather than assuming and make sure to record information about gender, trans status and sexual orientation on patients records. They also ask which ward people would like to use rather than assuming. This has helped their trans and non-binary patients to feel more

comfortable and feel as if their identity and needs have been taken into consideration.

As part of their work to improve LGBT inclusion they now have a ward that is gender neutral, people can choose to be in this ward if they would rather not be in a male or female ward.

People who are gender fluid and whose pronouns change have a note added to their care plan and they can record how often they would like to be asked about their pronouns.

The hospital has recognised that asking questions about gender identity and trans status was challenging at first as staff were not used to asking these questions. However, over time there was a cultural shift and these challenges were overcome. Receiving LGBT awareness training made it easier for staff to ask these questions.

Lavender Hill Group Practice- London

The GP surgery Lavender Hill Group Practice carries out trans status monitoring and sexual orientation monitoring. They ask about trans status and sexual orientation on new patient registration forms.

If someone discloses that they are trans on their registration form, they are contacted by the LGBT lead at the practice. They will have a discussion to see if the individual has any specific needs, for example around hormone prescriptions or Gender Identity Clinic referrals. They will also ask how they want their trans identity to be recorded. This can be coded into the system, can be placed as a pop-up note on the individual's records or can be put in the patient's consultation notes.

The practice has a recall system for cervical screening for trans men and non-binary people with a cervix. They make sure they send screening invite letters to their relevant trans patients, as trans people are usually not placed on the appropriate national screening registers. The practice nurse will discuss if they would like the screening done in the practice or if they prefer going to 56T (Dean Street service). They also use Jo's Cervical Cancer Trust videos to help to encourage people to attend.

They have had a few complaints from patients around the introduction of sexual orientation and trans status monitoring, including some criticism in their patient survey. In one instance when they got a serious complaint, they got in contact with the British Medical Association (BMA) who were very supportive and were able to help the practice to address and resolve the complaint.

The LGBT lead at the practice was able to support staff with any questions and concerns that they had when they introduced monitoring. The LGBT lead feels that there has been a culture shift, with staff now understanding how important it is to ask these questions and feeling confident and comfortable to do so.

Alongside monitoring, they have taken a number of other steps to ensure that their service are welcoming to all LGBT people. Staff wear the NHS rainbow badges, they have rainbow flags on their name badges, and they have the progress pride flag on their website (a rainbow flag that also includes black and brown stripes to represent LGBT People of Colour and pink, light blue and white stripes to represent trans communities).

This report has been commission by the NHS LGBT Team, to contact them please email: England.lgbtadvisor@nhs.net

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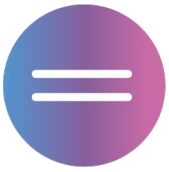
Promoting Safety

Encouraging Wellbeing



Achieving Equailty

We believe in a fair and equal society where all lesbian, gay, bisexual and trans people can achieve their full potential.

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