Experiences of health & care in Sheffield's trans community.

healthwatch Sheffield

SAYiT
registered charity no 1177477

TRANS ACTIVE

Contents

At Healthwatch Sheffield we want everyone to receive high quality health and social care services. We believe that people who use services can provide unique insights that can lead to improvements for all.

The experiences shared with us during the course of this investigation show how important it is to improve the accessibility and responsiveness of healthcare services for Sheffield's trans and non-binary residents. We learned about the profound impact of both good and bad experiences.

We've made recommendations to commissioners and providers based on what the people we spoke told us.

People who identify as trans or non-binary clearly face challenges in accessing good quality health care in a timely way. This report considers some of the causes, including broad structural issues, such as service design, workforce and changes in demand.

However, there are also social factors that play a huge part in people's experiences. Everyone involved in the NHS and social care must consider whether they are providing care to trans and non-binary people on an equal footing to people who are cisgender.

The national context of this report is 73% of trans people experiencing harassment in public spaces, with 10% reporting being victims of threatening behaviour.

41% of transgender people report attempting suicide, compared to 1.6% of the general population[1]. The NHS Long Term Plan[2], published in January, made clear that reducing suicides will remain an NHS priority over the next decade.

Within this context, NHS and social care providers have a duty to ensure that transphobia is not tolerated.

The experiences that we heard correspond with the view of the Chair of NHS National Clinical Reference Group for Gender Identity Services, who said that 'not treating people [for gender dysphoria] is not a neutral act—it will do harm'[3].

Doing nothing is not an option. We hope that by sharing this report with local commissioners and providers, things will begin to change for Sheffield's trans and non-binary community.

We would like to thank all of the people who contributed to this report, who attended our focus groups and events, told us their stories and provided their valuable insight and guidance.

Margaret Kilner
Chief Officer
Healthwatch Sheffield

[1] https://www.sheffield.gov.uk/jsna
[2] https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf
[3] https://publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/39002.htm

Who we are

We're here to help adults, children and young people influence and improve how services are designed and run. We are completely independent and not part of the NHS or Sheffield City Council. You can tell us about your experience of:

- Health services (GPs, dentists, opticians, pharmacies and hospitals)
- Social care services (care at home, residential and nursing homes, personal budgets etc.)

We collate the feedback you give us so we can provide evidence-based recommendations to the organisations that design, pay for, and run our local services.

SAYiT is a registered independent charity (no. 1177477) which has been running in Sheffield since 1999. We are an LGBT+ and sexual health charity working towards improving the lives of young people up to the age of 25, particularly those who are most vulnerable or marginalised people in Sheffield.

We run youth groups for people aged 11-25, provide 1:1 support, run a parents and carers group, work with queer, transgender and intersex people of colour (QTIPOC), facilitate a training and education programme, work with schools and organisations to set up gender sexuality alliances and contribute to the sexual health agenda in Sheffield.

Transactive aims to help the trans community in and around Sheffield socialise and improve their fitness and mental wellbeing through sport in a safe, relaxed environment.

We run T-Boys, which is a support and social group for any person assigned female at birth who considers themselves to be on the trans spectrum or is questioning their gender, including trans men at all stages of transition, non-binary, genderqueer and intersex people, and all other female towards male expressions of gender variance.

We also provide support to SOFFAs (significant others, friends, family and allies).

Terminology

When someone is **transgender**, it means that their sense of personal identity and gender does not match the sex assigned to them at birth.

Within this report, the term transgender, and its abbreviation, **trans**, are used interchangeably.

When someone describes their gender as **non-binary,** it means they feel that their identity isn't exclusively male or female gender. The term non-binary includes many different gender identities.

Some people who describe themselves as non-binary may wish to appear androgynous and adopt a gender neutral name and gender-neutral titles such as Mx instead of Mr or Ms. They might also prefer gender-neutral pronouns, such as them or they.

Pronouns are words we use to refer to people's gender in conversation - for example, 'he' or 'she'. Some people may prefer others to refer to them in gender neutral language and use pronouns such as they/their.

To **misgender** someone, is to use a pronoun or other form of address which does not match the gender with which that person identifies.

People express themselves in ways which are traditionally seen as masculine or feminine or by combining aspects of both. Some people choose to transition so that their outward gender expression more closely reflects their internal identity.

Other terms associated with being trans or non-binary include **gender nonconforming** and **gender fluid**.

The term **dead name** is used when a person is called by the name they were given at birth after they have changed their name.

The term cis gender refers to someone whose gender identity is the same as the sex they were assigned at birth.[4]

[4] For more information see https://www.stonewall.org.uk/help-advice/glossary-terms

Recommendations

We have made five recommendations, using the powers given to local Healthwatch, and based on the findings of our investigation.

Our recommendations are for local commissioners and providers, including:

- NHS Sheffield Clinical Commissioning Group (CCG)
- Sheffield Teaching Hospitals NHS Foundation Trust
- Sheffield Health and Social Care NHS Foundation Trust
- Sheffield Children's NHS Foundation Trust
- Sheffield City Council
- General practices, dental practices, pharmacies and opticians

We will ask key organisations to provide a response to the recommendations.

We have made a recommendation for increased support at a regional level so we will also seek a response from South Yorkshire and Bassetlaw Integrated Care System (ICS).

The Porterbrook Gender Identity Clinic is commissioned by NHS England and as such we will also seek a response from them.

Recommendations

Recommendation 1:

Increase support in Primary Care

Commissioners should consider increasing the support available within communities, keeping a close eye on the model being developed in Manchester as a test case for extended access in primary care.

NHS Sheffield CCG and South Yorkshire and Bassetlaw ICS can both play a role in training and supporting primary care staff to provide effective gender care that is accessible, safe and responsive.

Recommendation 2:

Proactively manage waiting times

Better waiting time information for Gender Identity Clinics should be made available to service users and front line staff.

Whilst it may take time for waiting times to be reduced, good information and communication can improve the experience for patients and staff.

We suggest Porterbrook Gender Identity Clinic introduces an automated waiting list information system, making creative use of existing technologies. For example, using SMS or an online portal to provide the up to date waiting list position of referred patients, could help reduce call volumes into the clinic and improve patient experience.

We also suggest making better use of the clinic web pages by providing up to date and detailed information about what to expect from the service, as well as links to good sources of information and support.

Recommendation 3:

Coordinate cultural change in health and care settings

Health and social care leaders need to recognise and respond to the cultural change required to ensure equality and equity to trans and non-binary patients.

There are great services and resources in Sheffield, but these are not always brought together and coordinated successfully.

The Rainbow Alliance LGBT+ network[5] across Leeds and York Partnership Foundation Trust is an example of a sharing network for providers, commissioners, and health and care staff, which ensures the availability of relevant information and training, improves knowledge of sexual/gender identity and provides knowledge of best practice when working with trans and non-binary service users, and the LGBT+ community generally.

It has produced a member-led action plan that shares the responsibility for LGBT+ inclusivity across a range of services in both Leeds and York.

Recommendation 4:

Do ask, do tell

Service providers should adopt a 'Do ask, Do tell' approach, asking service users what their preferred names and pronouns are, discreetly, but initially and directly, so that this can be established straight away.

When service user's names have been changed, their birth name should no longer be used.

Sharing of patients preferred names and pronouns should be enacted across electronic record systems so that confidentiality can be maintained.

Multiple gender options should be offered on all staff and patient record systems and data capture forms, including an option for those who wish to self-identify.

Recommendation 5:

Embed shared decision making and co-design

The people Healthwatch Sheffield heard from during the course of this investigation were articulate and highly knowledgeable. Often they have developed expertise because of their need to self-manage their care.

Providers and commissioners would benefit from developing constructive relationships with members of trans and non-binary communities, so that service users can be involved in decision making about all aspects of their care, and in the design and delivery of services.

[5] https://www.leedsandyorkpft.nhs.uk/get-involved/rainbow-alliance/

Why Healthwatch Sheffield decided to investigate

A primary aim of every local Healthwatch is to raise standards by listening to and acting on the views of people who use health and social care services.

For many reasons (which we will discuss later in this report), people who identify as trans and non-binary can find it difficult to have their views and experiences heard and understood.

During 2017, we were contacted directly by trans and non-binary service users about problems they were facing locally.

We spoke to organisations who support and represent the city's Lesbian, Gay, Bisexual, Transgender and Queer (LGBTQ) residents, who told us that they were aware that many young people and adults were facing barriers when accessing health services, both related to their gender identity and general health services.

Healthwatch Sheffield had not previously proactively gathered experiences in this area, and, considering that Sheffield has one of the country's eight Gender Identity Clinics, we felt it was timely to investigate.

The national conversation

In 2014-2015, Healthwatch England raised concerns with NHS England over Gender Identity Services, based on feedback from the local Healthwatch network.[6]

At this point the key concerns raised were:

- Waiting times for operations, which should be less than 18 weeks, were sometimes as much as 21 months.
- Demand for services for transgender people was increasing each year – but there were not enough specialist services to meet the demand in a timely way.
- There were not enough specialist consultants to deliver gender identity services.
- Communication with patients was poor, leaving people waiting for help unsure as to when they might get it.

NHS England published correspondence between the two organisations in an attempt to publicly address the concerns raised.

A Gender Task and Finish Group was established, which has since been replaced by the Clinical Reference Group for Gender Identity Services[7]. A series of blogs on the NHS England website documents developments over the past three years[8].

Around the same time, the House of Commons published The Women and Equalities Committee report on Transgender Equality, which highlighted the problems transgender people encounter when using NHS services.

[6]https://www.healthwatch.co.uk/response/2015-05-21/gender-reassignment-waiting-times-correspondence-nhs-england

[7]https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-e/e10/

[8] https://www.england.nhs.uk/blog/?filter-category=gender-identity

The NHS is letting down trans people: it is failing in its legal duty under the Equality Act. Trans people encounter significant problems in using general NHS services, due to the attitude of some clinicians and other staff who lack knowledge and understanding—and in some cases are prejudiced.

The NHS is failing to ensure zero tolerance of transphobic behaviour.

GPs too often lack understanding and in some cases this leads to appropriate care not being provided. A root-and-branch review must be conducted, completed and published by the NHS.[9]

The committee heard expert evidence that transgender people experience poorer health (both physical and mental health) compared to the general population, and that this is likely to be caused by the direct and indirect effects of inequality and discrimination.

NHS England said they would use the recommendations from this report in developing new service specifications for gender identity services.

In 2016, NHS England announced £6.5m of increased funding for Gender Identity Services for 2016/ 2017. This followed an allocation of £4.4m for 2015/16 to help bring waiting times down. In addition, Health Education England and NHS England began to explore ways to address recruitment gaps, staff retention issues, and training needs amongst teams delivering gender identity treatment through the Gender Identity Workforce Project[10].

Between July and October 2017, NHS England held a public consultation on specialised Gender Identity Services for adults based on two service

[9]https://publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/390.pdf

[10] https://www.england.nhs.uk/blog/vicky-lyons/

specifications: proposals for the provision of non-surgical interventions by Gender Identity Clinics; and proposals for services and interventions provided by 'designated surgical units'. There were over 800 responses to the consultation.

The independent analysis of the responses to the consultation[11], the report of the outcome of the consultation[12] and the new service specifications for Gender Identity Services for Adults (Surgical Interventions)[13] and Gender Identity Services for Adults (Non-Surgical Interventions)[14] have been published.

Changes to the service specifications include:

- Gender Identity Clinics will be renamed Gender Dysphoria Clinics.
- Self-referral to Gender Dysphoria Clinics will be permitted as long as the individual is registered with a GP.
- Providers of Gender Dysphoria Clinics will be expected to report against additional quality outcome measures.
- An evaluation of an 'early adopter site'[15] where the primary care model will be extended.
  This will involve a trained multi-disciplinary team based in primary care but linked to a Gender Dysphoria Clinic.
  If this proposal were adopted nationally, these teams could be located within the footprint of every Sustainability and Transformation Partnership in England.

[11]https://www.engage.england.nhs.uk/survey/gender-identity-services-for-adults/user_uploads/report-independent-analysis-consultation-responses-gender-identity-service-specifications.pdf
[12]https://www.engage.england.nhs.uk/survey/gender-identity-services-for-adults/user_uploads/gender-services-consultation-report-updated-equality-impact-assessment-v2.pdf
[13] https://www.england.nhs.uk/wp-content/uploads/2018/10/Gender-identity-services-for-adults-surgical-interventions.pdf
[14] https://www.england.nhs.uk/wp-content/uploads/2018/10/Gender-identity-services-for-adults-non-surgical-interventions.pdf
[15]https://www.gmcvo.org.uk/system/files/gm_ths_expressions_of_interest_dec_2018.pdf

NHS England's 'NHS Operational Planning and Contracting Guidance 2019/20' was published in January 2019, with 'Improving equity of access to services, including, for example, delivering faster access to high quality gender dysphoria services', a priority for specialised services commissioning[16].

In our area

Information from Sheffield's Joint Strategic Needs Assessment[17] tells us that statistics on the number of trans people living in England or in Sheffield are not routinely collected. However, the Gender Identity Research and Education Society[18] suggests a figure of around 0.6%, or 600 out of every 100 000 people.

Applied to Sheffield's population, the JSNA estimates 3418 transgender people live in the city.

Sheffield is within the Sustainability and Transformation Partnership footprint of South Yorkshire and Bassetlaw. The Partnership has been chosen by NHS England as one of the first areas to become an Integrated Care System (ICS).

With 1.5 million people living in the places that make up the ICS -Barnsley, Bassetlaw, Doncaster, Rotherham and Sheffield – based on a prevalence of 0.6%, approximately 9000 trans people live within the ICS footprint.

[16] https://www.england.nhs.uk/wp-content/uploads/2018/12/nhs-operational-planning-and-contracting-guidance.pdf

[17] https://www.sheffield.gov.uk/jsna

[18] https://www.gires.org.uk/

NHS England recognises a lack of reliable prevalence data but is clear that 'the number of people pursuing treatment options – the incidence of expressed need - is rising significantly'[19].

In Sheffield, Porterbrook Gender Identity Clinic[20] is based at the Michael Carlisle Centre in Nether Edge and is provided by Sheffield Health and Social Care NHS Foundation Trust (SHSC).

NHS England is responsible for the commissioning of Gender Identity Clinics (GIC) across England, and Porterbrook provides a national service.

This means that patients can be referred to Porterbrook from anywhere in the country and that local residents can request a referral to any of the other GICs within England.

The other Gender Identity Clinics in England are:

- The Tavistock & Portman NHS Foundation Trust, London (provides a Gender Identity Clinic for Adults and a Gender Identity Development Service for Children and Young People)
- Leeds Gender Identity Clinic, Leeds
- Northampton Gender Identity Clinic, Daventry
- Northern Region Gender Dysphoria Service, Newcastle
- Nottingham Centre for Gender Dysphoria, Nottingham
- The Laurels Gender Identity Clinic, Exeter

A workshop for Sheffield GPs on transgender prescribing was delivered by the Clinical Lead for the Porterbrook Gender Identity Clinic on 6 February 2019 as part of a Protect Learning Initiative event.

The workshop was arranged by NHS Sheffield Clinical Commissioning Group in response to requests from GPs, which indicates that they are keen to improve the care they are able to provide to trans patients. The event was well attended with 262 staff from GP practices taking part.

[19] https://www.england.nhs.uk/wp-content/uploads/2018/10/Gender-identity-services-for-adults-non-surgical-interventions.pdf

[20] https://shsc.nhs.uk/service/gender-identity-service/

Prescribing guidelines can be accessed through the Porterbrook Gender Identity Clinic website[21].

In 2012, Yorkshire and Humber Regional Equality and Diversity leads agreed to set out a Trans Patient Protocol[22] to support the provision of high quality care to transgender people using NHS services in the region and in recognition of the Equality Act 2010[23].

The Equality Act 2010 protects people on the basis of 'gender reassignment' from direct and indirect discrimination and harassment. There is a proactive duty on public organisations to promote equal opportunities, foster good relations and eliminate unlawful discrimination.

The protocol was designed to be used as a template and be adapted to support the development of local policies and good practice.

[21] http://shsc.nhs.uk/wp-content/uploads/2018/04/V10-22-01-18-TG-SCP-Trans-woman-Sheffield-Logo.pdf http://shsc.nhs.uk/wp-content/uploads/2018/04/V12-22-01-18-TG-Trans-man-Sheffield-Logo.pdf

[22] www.barnsleyhospital.nhs.uk/equalitydiversity/files/2012/01/Providing-Hospital-Services-to-Trans-Patients-Protocol-2012.pdf

[23] http://www.legislation.gov.uk/ukpga/2010/15/contents

How did we investigate?

We contacted local groups who support and represent trans and non-binary adults and young people, SAYiT[24] and Transactive, who agreed to work with us to find out more about people's experiences.

Grace Darbyshire, our Engagement Officer and lead for Young and Student Healthwatch, participated in Future in Mind LGBT+ & Mental Health Awareness Training, and, with Healthwatch Sheffield Community Research Volunteers, attended the Future LGBT+ Leaders conference hosted by SAYiT. Staff and volunteers felt it was important to develop at least a basic understanding of the breadth of the issues faced by the LGBT+ community before beginning this piece of work.

We also took some time to find out how trans and non-binary service users wanted us to work with them to help make their voices heard. Our partner organisations introduced the idea to their groups, explained the role of Healthwatch, discussed how the engagement could work, and what was important to them.

Grace worked closely with Lee Lester from SAYiT and Matilda Moulam and Annabelle Wong, Healthwatch Sheffield Community Research Volunteers, to plan appropriate and welcoming engagement activities, in settings where participants would be relaxed and comfortable sharing sensitive information.

Two focus groups were held: the first, on 14th March 2018, with some of SAYiT's trans service users; and the second, on 16th April 2018, with the Transactive community group 'T-boys'.

SAYiT and Transactive publicised the focus groups widely across their networks. There were also opportunities for people who didn't want to, or couldn't attend in person, to submit their views online.

Following the focus groups, Grace met with the Business and Performance Manager at Porterbrook Clinic. The

[24] https://sayit.org.uk/

Porterbrook team were supportive of our investigation and arranged for Healthwatch Sheffield to listen to the views of service users directly on 19th April 2018, either in the waiting room or a private side room.

The final event was a workshop held at The Circle on 30th April 2018. Here, we brought together trans and non-binary service users, clinical staff and operational leads from health and care services.

We publicised this workshop widely and invited representation from local adult NHS trusts (Sheffield Teaching Hospitals NHS Foundation Trust and Sheffield Health and Social Care NHS Foundation Trust) Porterbrook Clinic, NHS Sheffield Clinical Commissioning Group (CCG), Sheffield Children's NHS Foundation Trust and Sheffield City Council.

The aims of our engagement were to:

- Increase understanding of trans and non-binary people's experiences of using local health and social care services.
- Bring trans and non-binary service users together with staff from provider and commissioner organisations to identify problems, solutions and best practice.

Findings

Key themes from the focus groups

Eight trans and non-binary young people aged between 18-25 attended the first focus group.

Five members of Transactive, aged between 19-54 attended the second group.

On both occasions semi-structured conversations were facilitated by our Engagement Officer, which focused on seeking health care related to gender identity, Gender Identity Clinics, seeking general medical services and best practice for health and care staff.

The most powerful theme throughout our engagement was fear of accessing services - a fear of discrimination and of unfair treatment from providers. In some cases the fear was based on previous experiences in health and/or social care settings and in others due to prejudice experienced in other contexts.

Perhaps because of these deep seated fears, positive experiences meant a great deal to the people we heard from. Participants were quick to speak about occasions where health and social care staff had been supportive and keen to understand. Sadly, it was rare that we spoke to a service user who had a wholly positive experience.

See appendix one for examples of the experiences shared.

Awareness of trans and non-binary identities

A recurrent theme was a perceived lack of awareness of trans and non-binary identities among health and care workers. This included LGBTQ issues in general, rights and entitlements, awareness of what services exist and the referral process.

This lack of understanding was considered to be a barrier that can prevent or delay access to appropriate care. This was experienced within Sheffield inpatient and outpatient hospital settings and in primary care.

Several incidents were discussed in which participants experienced discrimination or felt scared during visits to hospital due to what they perceived to be a lack of knowledge or reluctance from healthcare staff to engage with the service user's needs.

Participants thought that training and clear policies regarding the treatment and care of trans patients was desperately needed if they are to be "treated like any other patient, with respect".

As a specialist clinic, Porterbrook employs a transgender peer support worker. The support this worker provides to isolated trans and non-binary people is seen as extremely valuable, however there were concerns that one person could not meet the demand for support.

Terminology and gender pronouns

Participants told us that in many cases service providers refused to use or chose not to use their preferred name or pronouns.

The lack of inclusivity regarding gender and title options on forms being used in different service points contributes to this problem.

A general lack of recognition of non-binary identities was highlighted and a perceived reluctance by GICs to acknowledge genders other than exclusively male or female.

Communication

Participants felt that communication among and between service providers as well as with service users could be much better. They felt this would help service providers understand what service users need, avoid misunderstanding and most importantly, create a respectful and comfortable environment.

Several participants said that they valued being treated respectfully by staff at the Sexual Health Clinic in the Royal Hallamshire Hospital, and that other service providers could learn from their approach.

The lack of a shared patient record system between services was raised: “You have to out yourself every time” (at every separate service). People felt that this compromised their privacy in a supposedly confidential setting.

Waiting times

Participants were disappointed yet accepting of the long waiting times for an initial appointment, but felt that a lack communication during this period and between appointments causes distress, and could be more easily resolved than the waiting times themselves.

They thought an automated system to check your place in the ‘queue’ would be helpful. Some service users said that they felt this would ease pressure on the telephone system at Porterbrook, as less people would be phoning to find out how much longer they have to wait.

In general, participants felt that services related to gender identity were placed at a lower priority. They want to see more resources invested so that better support for transgender people is available.

Consequences of waiting for treatment

The negative impact of long waiting times on mental health was highlighted by participants. The lack of sufficient support during the waiting period was described as leading to a “sensation of abandonment”.

Participants also spoke about making suicide attempts in this period, self-harming and using hormones bought online and without medical supervision. Participants felt that these risks aren’t sufficiently taken into account by services.

Staff attitudes

An open attitude was seen as essential for providing high quality services. Participants said they value being treated with respect and understanding and that too often staff made assumptions based on stereotypes.

Participants agreed that they’d rather someone ask, for example, which pronoun and name they should use.

Fear and stigma

Participants discussed fear of accessing NHS services as a barrier to timely diagnosis and treatment. When the initial experience is poor, this increases worries about being judged by healthcare professionals.

Similarly, having a mental health problem was seen as a barrier to receiving a diagnosis. Mental health problems are often are seen by professionals as a cause of gender dysphoria, but participants felt that mental health problems often arose from denial of their gender identity.

Healthcare staff as 'gatekeepers'

Participants who had sought help from the NHS to transition described experiences of 'interrogation', deeply personal questioning that felt out of the individual's control, and a sense of powerlessness.

Listening event at Porterbrook Clinic

By prior arrangement, Healthwatch Sheffield's Engagement Officer visited the Porterbrook Gender Identity Clinic at the Michael Carlisle Centre on the morning of Thursday 19th April 2018.

Service users were informed by staff when they arrived for their appointment, that there was an opportunity to share their views. Six service users shared their views and experiences.

The questions from the focus groups were used as prompts for conversation and to initiate discussion. Individuals described their experiences at length, many of which echoed those that we had heard from participants of the focus groups.

Porterbrook Clinic was described as generally providing a good service, with friendly staff, but even in this setting, some service users described instances where they felt misunderstood by staff and suggested that more in-depth training be provided for staff working with transgender and non-binary patients.

Long waiting times for initial assessments and then between appointments, was again cited as problematic. Here we also heard about extensive waiting times for surgery.

People said that communication between the service and patients was really crucial, particularly in the context of long waiting times, and that a lack of communication could cause great distress.

We heard more about the serious effects that long waiting times can have on both physical and mental health, with self-medicating (for example sourcing hormones online), self-harm and suicide considered to be the unintended outcomes.

See appendix one for examples of the experiences shared.

Workshop: Barriers accessing services for trans and non-binary communities

Our final engagement event brought together trans service users and their families with health and social care staff.

28 people attended the workshop, including representatives from a wide range of backgrounds; staff working in patient experience, engagement and equality in local and regional NHS Trusts, local consultants who were working frequently with trans patients, and representatives from Sheffield City Council, the University of Sheffield and the voluntary sector.

We were pleased that several trans and non-binary service users who had attended the focus groups, also participated in the workshop.

The workshop structure was informed by the views of service users and group leaders from Transactive and SAYiT.

The focus of the event was to share what we had learnt from local service users and to identify ways in which experiences of care can be improved.

We also took the opportunity to provide a platform for our partners to share information about their services and the people that they work with.

Health and social care staff commented on how helpful they found this introduction and there were many pledges to continue conversations about awareness and staff training outside of the workshop.

Participants were then invited to work in groups to read and respond to anonymised case studies drawn from the stories we had heard during our engagement.

Our groups were asked to consider the problems and their causes, whether and how the problems could have been avoided and what solutions could be put in place.

Summary of responses to the case studies	
Primary problems and causes	**Possible solutions**
The amount of barriers (and resulting distress) involved just to access a service in the first place	Education and training for all staff - both on non-discriminatory practice and the serious consequences of stigma and discrimination, such as self-harm and suicide.
Lack of awareness and understanding shown by staff which could have been caused by a lack of training.	
Patronising and sometimes discriminatory attitudes and behaviours displayed by staff.	
Being required to 'fit into a box' - both literally, with the options to record gender available on NHS forms and records, and figuratively, in the way people are expected to present as a gender with which they do not identify.	Improve locally controlled NHS forms and ask for improvements to electronic patient record systems to include more gender options.
Long waiting times between appointments.	An automated system could tell service users where they are on the waiting list, providing reassurance of progress and relieving pressure on administrative staff dealing with phone calls to find out this information.
Reception and administrative staff not always able to be responsive as they appear to be 'overwhelmed'.	
Isolation and fear of leaving the house due to lack of support during transition.	Access to mental health care (if required) is addressed prior to initial appointment at a Gender Identity Clinic. Employ outreach workers and/or peer support workers to provide support and information to isolated individuals.
The current approach isn't proactively supporting older people, who may not be aware of recent developments in treatment options.	

Service users self-medicating by using hormones purchased online, with no medical oversight.	Education and training for health care professionals on the specific health issues facing trans and non-binary patients. Access to support and advice from specialists. Up-skill staff in primary care (GPs and practice nurses) to support service users during the long waits for appointments at Gender Identity Clinics.
Fear and anxiety based on lack of trust and poor previous experiences prevent people seeking treatment for general medical issues.	
Lack of knowledge amongst health professionals about hormone treatments and their interactions can lead to treatment being stopped or withheld.	
Lack of information and options shared with patients, for example not being given a full range of surgical options or photographic examples of the surgeons work.	Better online and face-to-face information. More time within appointments to consider a full range of options.

This first activity focused on specific cases, and generated ideas about practical changes that could be made at a local level.

The second activity focused on five overarching themes drawn from our engagement with trans and non-binary people. We introduced these themes and gave examples of relevant experiences.

Participants were encouraged to move around the room to focus on the theme where they could contribute the most and/or had the most control over. Participants were asked to record their discussions in response to the question ‘What can we do together to solve these problems?’

Key theme	What can we do together to solve these problems?
Awareness of trans and non-binary identities/gender terminology	• Establish and promote the use of on-line training on trans and non-binary awareness and respect - for staff in all public facing roles and in all areas. • More education and training for primary care staff, and GPs in particular, on how to support trans and non-binary patients. • Training that empowers health and social care staff to challenge ignorance and discriminatory practice when presented with it. • Prioritise knowledge of gender related medication in hospital settings. • As the demand rises, ensure that training for the next generation of health and social care staff includes trans and non-binary awareness. • Sufficient time allocated for training and thinking time. • Recognise that service users may need time to develop a rapport and the trust to tell their story - managers should allow staff the time to listen. • Recognise at leadership level that cultural change is required.
Disjointed care/communication	• Patient experience always at the centre of care. • Clear pathways are needed, for people to be able to see how their care will progress. • The 'final steps' of treatment (for people that get to that point) are mostly well coordinated, but the wait and poor experience getting there have an impact that should be recognised. • During transition, if primary care isn't right, everything else becomes a problem, people require support in living their true gender 'full time' particularly during the first year.

	• Trans and non-binary representation on Patient Participation Groups and experience groups.
Waiting times	• More education and training for primary care staff, and GPs in particular, on how to support trans and non-binary patients, so that referrals are made more promptly. • Increase the number of specialist staff employed, specifically surgeons and counsellors. • Review the current framework to increase the treatments that can be provided in a primary care setting, for example a GP with a Special Interest refers to a Gender Identity Clinic but in the meantime, prescribes hormones to necessary level. • Increase GPs awareness of local support services, for example SAYiT and Transactive.
Consequences of waiting for treatment	• 'Harm reduction' advice and information should be made available for people who instigate their own medication regime. • Commissioners incentivise GPs to train as GPs with a specialist interest in gender identity healthcare. • Specialist mental health treatment assessment. • Expectation that health and social care staff will recognise that self-harm often gets worse and that related desperation can lead to more and more dangerous risk taking behaviour.
Fear and stigma	• Be proactive in stating commitment to supporting trans and non-binary people, for example by displaying posters in waiting rooms. • Service users proactively share experience of good practice, for example with Heathwatch Sheffield, if a GP or healthcare provider is particularly informed and responsive.

	• Improve online information about Gender Identity Clinics and the referral and treatment process. • Information pack to be provided at the point of referral with practical information about the Gender Identity Clinic, sources of support and information and the process. • Group information and discussion workshops for patients while they are considering or waiting for treatment. • More peer support workers. • Provide testimonials - real stories from people who have been through the process.

To end the workshop, we circulated a flyer for attendees to take back to their workplaces or to share with their own health care provider, summarising some examples of best practice in health and care settings, using direct quotes from service users.

The flyer was circulated by NHS Sheffield CCG to all staff and to primary care staff through their newsletter as an immediate action following the workshop.

The flyer can be found in appendix two.

Feedback from workshop evaluation:

"I will be taking all I learnt today back to adult social care and we will be proactive in trying to stop the things I've heard about today before they become issues."

"Great variety...personal stories and information about services. Great to see people from different backgrounds coming together - NHS, service users, universities."

"Most of the issues raised and discussed I had not thought of!"

"Thank you for putting this event on. It was really heartening and useful too."

Next steps

We want everyone who shares their experiences with us to understand the difference their views make.

We will invite the relevant providers and commissioners to respond to the findings and recommendations of this investigation.

This will help us to see how they will use local people's experiences to shape the health and care support provided in the future.

SAYiT and Healthwatch Sheffield wish to support the implementation of our recommendations on an ongoing basis.

In particular, in partnership with providers, commissioners, and health and care staff, we will initiate a network inspired by the Rainbow Alliance LGBT+ network[25] across Leeds and York Partnership Foundation Trust.

[25] https://www.leedsandyorkpft.nhs.uk/get-involved/rainbow-alliance/

Appendix 1

Examples of experiences shared during engagement events. Some information has been removed to ensure anonymity.

Awareness of trans and non-binary identities

‘My GP told me “you don’t need to do this; I don’t believe it’s a real thing” (being trans/non-binary). They also brought up another trans patients name who attends that doctors.’

‘Before I got referred here, I went to my doctor, who said “That’s not a health problem, you’re just gay.” I got another GP who was more understanding but I was still really afraid of being discriminated against.’

‘What prevents me from accessing services is not knowing how staff members will react, and how much knowledge about trans issues they will have.’

‘My GP is supportive but doesn’t have a lot of knowledge, so I have to keep informed about what I need i.e. blood tests, prescriptions etc. This isn’t a barrier for me personally, but it could be for someone who can’t advocate for themselves as well.’

‘My doctor was very hesitant, they said it “wasn’t a real thing” and so I had to change GP. The doctor would refer to me as “young lady” when I know that’s not me.’

Terminology and pronouns

‘[Discussing sexual health clinic] They don’t judge you. Pronouns are well adhered to.’

‘Before I changed my name legally each time I went to the GP I had to re-tell them my preferred name and they didn’t keep it consistently. At some places there is no scope for a preferred name.’

‘[When being asked about sex on a form] Is this important? Do I need to put it because of medicines reacting to biology or do I be my real self?’

Communication

‘I am still eligible for smear tests but because my NHS number has now been changed, no dropdown option appears for me. In this way, I fall through the gap. I had to remind them about it. Steps can be taken to prevent this, easily.’

‘My GP’s always been really good about it. CAMHS sent a letter to my GP so everyone called me by my new name.’

‘All of the computer systems aren’t linked up so you have to out yourself every time [in different health care settings]. It took so long for them to sort it out and when they call your name it’s this feeling that everyone will know. There’s no privacy. The system seems unhelpful.’

‘Something that I wasn’t expecting which was good was that I needed a procedure and I was worried that I would have to have an internal examination. But on the day they told me that I didn’t have to have it so this would have been good to know beforehand. You could be told about the different options which I think would encourage more people to have the procedure.’

Waiting times

‘I think they’ve finally realised, hold on these people really need us. There is still a long wait between appointments.’

‘Waiting times can be well over two years for most people, prescription prices and travel costs are a lot, since there are so few clinics. It costs me over £50 to travel to my appointments each time so if I’m low on money I won’t be able to go.’

‘I was originally told [that the waiting time would be] about 8 months for my first appointment and ended up waiting for nearly two years.’

‘Waiting times are long but once I got the appointment it was quite quick. It might help if you could have some indication of where in the queue you are. It’s the not knowing that’s the problem.’

‘I had a two year wait for my first appointment after my referral to [Gender Identity Clinic]. The service here has been really positive, but I did have an eight month wait for a second opinion. There is a lack of education generally. No one

really knows what the steps are.'

Consequences of waiting for treatment

'I was lucky as I could afford private whilst waiting for the GIC. Then I eventually stopped that when the GIC kind of caught up. There was a stark difference in the consultations, the private sector seemed to take what you're saying as given and the truth and see you as the whole person whereas the NHS seemed a lot more clinical.'

'A lot of time it feels like they don't even care I'd already tried suicide a few times and I was just left to rot. Better communication would be great.'

'I have depression and anorexia/bulimia due to my being trans, to try losing the fat in my breasts.'

'Being new to it I found that there was no support in the waiting period. My major concern is that I have a lot of other mental health problems and being left alone in that waiting time is a problem.'

'This whole process has put my life on hold. I just want to get on with things.'

'My mental wellbeing is good; it was hard when I was finding myself, but now I've come out, everything is a lot easier. I just think people need help recognising the behaviours earlier.'

'It hasn't been easy to get here. When you are in the system, it is relentless and torturous. The way it wears you down. I'm in groups on Facebook where we talk about it, and support each other. It's the younger guys I worry about, as they don't have real support networks. Self-harm and suicide is a big problem for them. Feelings become heightened.'

'There needs to be strategic understanding. Lives are at risk. I am very robust, but it has often made me feel like ending my life.'

Staff attitudes

'Sometimes a bad attitude can undermine what little self-confidence a person has. Everyone here and in the NHS needs trans inclusivity training, especially those working in GICs. It should be a basic requirement. They have [staff group], but sometimes they give us the wrong information; they

give people the optimistic version, there shouldn't be false hope. We need realistic times, and facts. Treat us like adults. Don't break our confidentiality.'

'I have been to [Gender Identity Clinic] four times before. The staff are all good and helpful. They answer my questions; it feels like they are here to help.'

'It recently took me three trips to A&E to get antibiotics for an infection following my top surgery. The doctor wouldn't even look at my chest he just put the antibiotics onto the end of my bed and said "I don't even know if they'll work".'

'My GP wouldn't do my bloods because I was self-administering hormones. But some do it so they're just choosing not to.'

'I had a bad experience at [local hospital]. I waited for two hours in a private room and when I was finally met by the doctor she was annoyed that I had waited even though I had been told that I could wait and I needed to get my hormones. She showed me my scan and when I asked a question she said "this isn't a private hospital we don't have time to go into these things." I was just dismissed.'

'I had an experience where I needed a catheter to be removed and the consultant at the GIC said all you need to do is go to the [hospital in Sheffield]. When I got to the [hospital in Sheffield] the nurse took me into a side room and said "I don't treat people like you, you're not on my list, I wouldn't know what to do with you." I felt really upset and went with a friend back to the GIC who had to ring the [hospital in Sheffield] and literally shout at about five different people to get them to agree to take out the catheter. The whole experience was really scary.'

Fear and stigma

'Imagine living every day and you can't look in the mirror because it makes you want to pull your eyes out and they don't care.'

'Before coming out it makes you depressed like the whole world is being pulled out from under you and your thinking who is going to accept it. Then once you're out it's so stressful, it would make me feel physically sick. Your mental state just breaks you down. Being brave breaks you down.'

‘One of the main reasons I didn’t get help with mental health was because I thought it would show up when I went to the GIC and that it would be held against me. I was stuck in a vicious cycle.’

‘I’d love to go swimming but I’m too scared.’

‘You are always thinking “What if the doctor outs me?”’

‘Healthcare staff as ‘gatekeepers’

‘I was anxious to make the most of the appointment because there was pressure to say the right thing at the right time.’

‘To begin with it was a very stressful experience. I felt like I was being thrown into the deep end and bombarded with questions. The initial assessments were more like an inquisition and there was a clear bias towards binary genders. Later treatment was much better though.’

‘There is an excessive amount of staff that you have to see, I saw seven people. Two at my GP, three at [out of area Gender Identity Clinic] then two at [Sheffield Gender Identity Clinic]. It feels like they’re cross-examining you.’

‘I’m scared to go to my GP for being ill in case they blame it on my hormones and then take them away from me.’

‘[On Gender Identity Clinics] You have a meeting with someone and then they all go away and discuss you and decide if you’re allowed the treatment. It seems archaic. The panel meet every three months and I’ve had friends that have their meeting on the afternoon after they’ve met so they have to wait another three months and it just holds everything up.’

‘[On Gender Identity Clinics] They have been pretty helpful but sometimes the questions do get a little too personal, it’s sort of like is this really necessary?’

Appendix 2

Some thoughts to take away – suggestions of best practice from Trans and Non-binary service users.

Dignity and respect for the patient:

"Don't be afraid of a conversation. If you don't know, just ask. Talk to me about it"

"To be treated like any other patient, with respect"

"Talk to us, find out what we feel, if there's anything you can do then and there, even as small as noting pronouns or offering to be their preferred doctor, then do it"

Transparency about the service available:

"I don't want to hear the optimistic version of what could happen to me. It gives me false hope; tell me realistic times, and realistic facts"

"Give better information about waiting times and also try to keep the websites up to date"

Using correct genders, pronouns, and names:

"Gender us correctly, if we've changed our documents, don't mention our dead name"

"At some places there is no scope for a preferred name. This needs to change"

"Your forms should be gender inclusive"

Some training and general awareness:

"Education on gender diversity. I may be trans but we are all very different"

"Be knowledgeable about trans people (e.g. using chosen name/pronouns, knowing what impact dysphoria related issues may have, being aware of physical transitioning options, being aware of practical interventions such as chest binders, packers, tucking...But also don't be afraid to ask the individual if unsure what situation applies to them specifically"

"They need to know about trans and non-binary people and be receptive to learn."

Clear communication:

"There needs to be more communication between different departments in the NHS"

"Occasional calls to reassure you that you're still on the waiting list (for the Gender Identity Clinic). Update on how far along you are. It shows that they still care."

"There needs to be communication and reassurance while waiting, and in-between appointments"

Contact details

Healthwatch Sheffield

The Circle, 33 Rockingham Lane, Sheffield, S1 4FW.
Phone: 0114 253 6688
Text only number: 07415249657
Facebook: www.facebook.com/HealthwatchSheffield
Twitter: www.twitter.com/HWSheffield
Email: info@healthwatchsheffield.co.uk
Web: www.healthwatchsheffield.co.uk/

SAYiT

Scotia Works, Leadmill Road, Sheffield, S1 4SE
Phone: 0114 241 2728
Facebook: https://www.facebook.com/sayit1177477
Twitter: www.twitter.com/SAYiTSheffield
Email: info@sayit.org.uk
Web: https://sayit.org.uk/

Transactive

Phone: 07713899577
Facebook: www.facebook.com/transactive
Email: transactive2014@gmail.com
Web: trans-active.co.uk