Trans and Non-Binary Health Experiences

Healthwatch Lewisham

May 2024

Your Voice in Health and Social Care (YVHSC) is an independent organisation which gives people a voice to improve and shape services and help them get the best out of health and social care provision. YVHSC holds the contract for Healthwatch Lewisham (HWB). HWB staff members and volunteers speak to local people about their experiences of health and social care services. Healthwatch engages and involves members of the public in the commissioning of health and social care services, through extensive community engagement and continuous consultation with local people, health services and the local authority.

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Glossary of terms

Bridging prescription: A temporary prescription of hormone replacement therapy (HRT), typically oestrogen or testosterone, issued by a GP to a patient who is waiting for specialist treatment, usually at a gender dysphoria clinic.

Cisgender: People whose gender identity matches the sex they were assigned at birth.

Cisnormative: Is an assumption that everyone is, or should be, cisgender. This can affect how care is given, or what options are available in health services.

Gender Diverse: An umbrella term for array of gender identities and expressions, including transgender and non-binary, that are not cisgender.

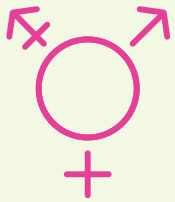
Gender Dysphoria Clinic: Specialist services for individuals undergoing gender reassignment. There are two London Clinics, Tavistock and Portman trust at 120 Belsize Lane, NW3 5BA is taking accepting new patients. Transplus at 56 Dean Street, W1D 6AQ, is not accepting new referrals. (GDCs were previously called Gender Identity Clinics).

Gender reassignment: The medical process of transitioning. This can involve surgery or hormone replacement therapy.

Hormones: Molecules that can affect sexual desires, change emotions, and induce bodily changes. Transgender people will commonly undergo Hormone Replacement Therapy to help them medically transition. Transgender men commonly take a form of testosterone. Transgender women commonly take a form of oestrogen. These can be taken as a pill, gel, or injection.

LGBT+:	Lesbian, Gay, Bisexual, Transgender. The plus is used to include other people whose sexuality is not heterosexual or whose gender is not cisgender.
Non-binary:	People whose gender identity is not solely male or female and who are not on the gender binary.
Pride in Practice:	A training scheme launched by the LGBT+ Foundation, based in Manchester. It teaches health professionals about LGBT+ people and their health needs.
Shared care agreement:	An agreement between a Gender Dysphoria Clinic and a GP, or a private care provider. The clinic will ask the other provider to take responsibility for blood tests and prescribing, including prescribing hormones.
Transgender (or trans):	People whose gender identity is different to the sex they were assigned at birth.
Transitioning:	When somebody moves away from the gender, they were assigned at birth toward a preferred gender identity.
Transphobia:	A rejection of trans identity and a refusal to acknowledge that it could possibly be real or valid.

Executive Summary



We have been listening to trans and non-binary people who access care services in Lewisham and we are making recommendations to commissioners and health service providers based on the things we heard.

This report contains general recommendations, but individual commissioner and providers will receive additional tailored recommendations.

We heard a mix of positive and negative stories from 20 trans or non-binary people who access care services in Lewisham. From these stories we identified that attitudes, services, and systems in Lewisham health services were leaving our participants with unmet needs. GP services and a lack of knowledge from health providers were the things our participants usually talked about in the most negative light.

Local services have made a good start in improving health experiences for this group, but more needs to be done. This is why we are making recommendations to commissioners, health service providers and the South East London Integrated Care System.

These changes will mean that trans and non-binary people have more options to access care and a better understanding of what options are available to them. It will also mean that health service providers will be more confident when treating this group.

If these changes are followed, it will reduce the large health burden faced by this population.

Our Recomenndations

We go into greater detail about these recommendations on page 48.

Staff

1. Train health professionals.

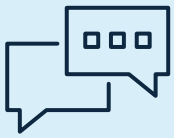
2. Incentivise health professionals.

Services

3. Make existing care services more inclusive.

4. Expand services that work.

Signposting



5. Improve and increase signposting.

Improving

6. Conduct more research into additionally marginalised communities.

Introduction

Who is Healthwatch Lewisham?

Healthwatch Lewisham is a health and social care champion for people in the borough of Lewisham. We help people find trustworthy information about services. We also have the power to make sure decision makers in the NHS and in other places listen to what people are saying about health and social care.

We are here to listen to the issues that really matter to local communities, and we believe that every story matters. Sometimes this means listening to people, sometimes this means speaking to lots of people and writing a detailed report to give recommendations to organisations that design, pay for, and run our local services.

In this report, we spoke to **transgender**, **non-binary**, and **gender diverse** people who live in Lewisham or access care in Lewisham to hear what they had to say about health services. We also collaborated with some gender diverse community members, who advised and helped us choose the right questions. They also helped us by co-leading our interviews. There were other people we spoke to, including some medical professionals that organised, or went through, **Pride in Practice** training.

The trans and non-binary population

Our best estimate for the number of transgender people in the UK is 262,000, from the last census, though this is likely to be an underestimation.[1]

The Equality act prohibits discrimination on the basis of protected characteristics, such as gender reassignment.[2] The Public Sector Equality Duty requires public services to eliminate discrimination, harassment, and victimisation related to these characteristics.[3] Gender reassignment is one of these protected characteristics.

The Government noted that there was a lack of research into the health service experiences of gender diverse people, and a subsequent survey of 108,000 LGBT+ people led to the LGBT action plan. This plan ensured that more would be done to meet the health, safety, and community needs of gender diverse people so that everyone could feel 'safe and happy to be who they are without judgement or fear.'[4]

In response, Lewisham Council, as part of their Safer Stronger Communities strategy, committed to working with groups giving voice to the borough's diverse LGBT+ community and actively challenging all forms of discrimination.[5] This was echoed by the Lewisham LGBT+ Joint Strategic

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[1] Office for National Statistics, 'Quality of Census 2021 gender identity data (2023) <ons.gov.uk/peoplepopulationandcommunity/culturalidentity/genderidentity/articles/qualityofcensus2021genderidentitydata/2023-11-13/pdf> [accessed 28/02/2023].

[2] UK Government, 'Discrimination: your rights' (2012) <https://www.gov.uk/discrimination-your-rights>.

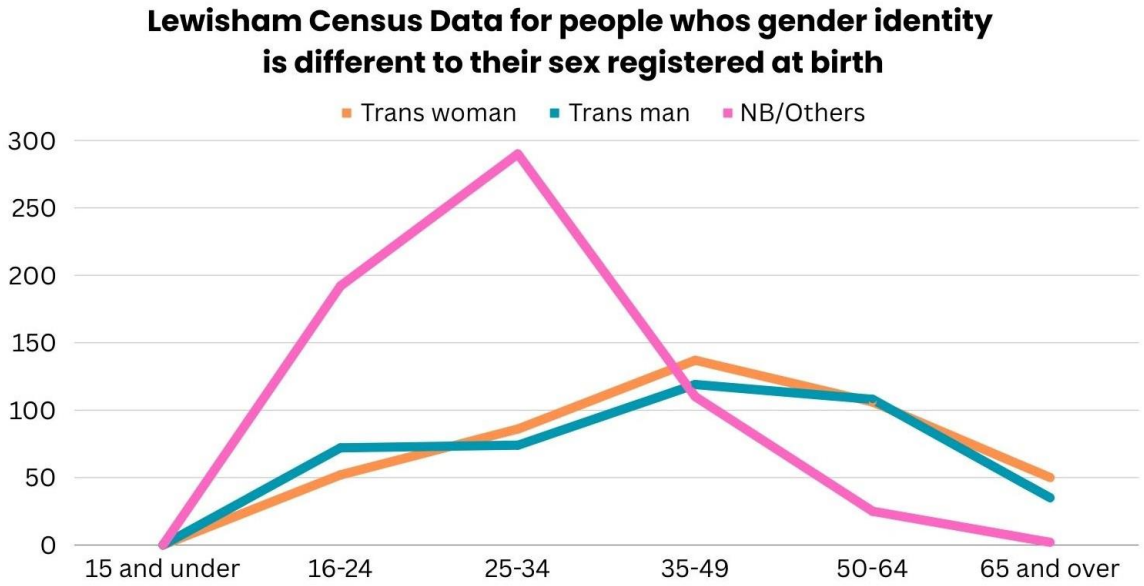
[3] Uk Government, 'Public Sector Equality Duty: guidance for public authorities (2023) <https://www.gov.uk/government/publications/public-sector-equality-duty-guidance-for-public-authorities/public-sector-equality-duty-guidance-for-public-authorities>.

[4] GEO (Government Equalities *Office), LGBT Action Plan: Improving the Lives of Lesbian, Gay, Bisexual and Transgender People. (2018)* https://assets.publishing.service.gov.uk/media/5b39e91ee5274a0bbef01fd5/GEO-LGBT-Action-Plan.pdf, page 4.

[5] London Borough of Lewisham Council Safer Stronger Communities Select Committee, *Provision for the LGBT+ Community in Lewisham Scrutiny Review* (2019)

Needs Assessment, published in 2021, that recommended more data collection, signposting, engagement, and training that would benefit the LGBT community.[6]

In 2023, a follow up document recommended that the integrated care board review additional issues faced by transgender people living in Lewisham, due in part to new data from the census.[7] Almost 2500 people in Lewisham said on the census that their gender identity differed from the sex they were registered at birth. This is 1.02% of the local over-16 population, which is double the national average. This also varies considerably by age. Younger people were more likely to identity as non-binary, for example.[8]



https://councilmeetings.lewisham.gov.uk/documents/s63183/04ProvisionfortheLGBTCommunity6monthupdateReportSSCSC120319.pdf, para. 5.

[6] London Borough of Lewisham, *Lesbian, Gay, Bisexual, Transgender, Queer Plus (LGBTQ+) Joint Strategic Needs Assessment* (2022) <https://councilmeetings.lewisham.gov.uk/documents/s108326/Item7_JSNAReport080323.pdf>, page 26.

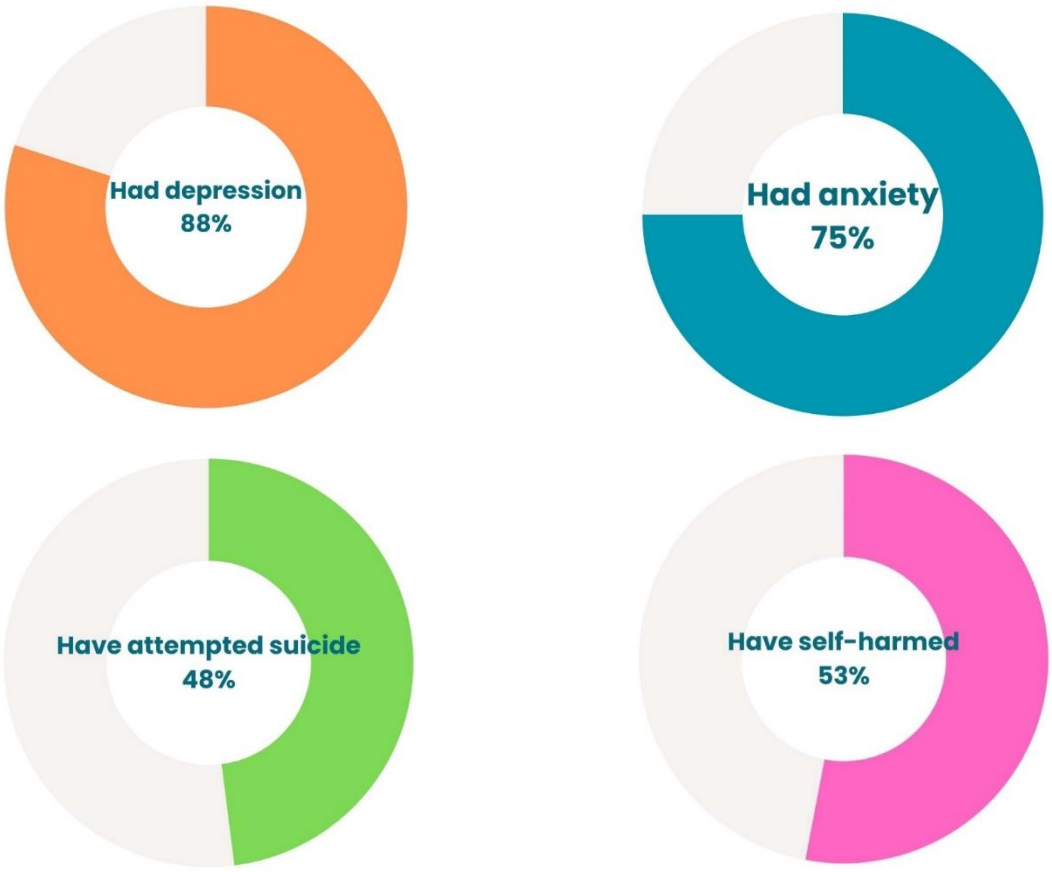
[7] London Borough of Lewisham Health and Wellbeing Board, *Transgender Population - Follow up from Lesbian, Gay, Bisexual, Transgender and Queer Plus (LGBTQ+) Joint Strategic Needs Assessment (JSNA) Report* (2023), <https://councilmeetings.lewisham.gov.uk/documents/s110861/Cover%20Report%20Transgender%20Population%20Paper%20for%20July%202023%20HWBB.pdf>, para. 5.

[8] Office for National Statistics, 'Gender Identity by Age' (2023), <https://www.ons.gov.uk/datasets/RM035/editions/2021/versions/2>.

Health Inequalities

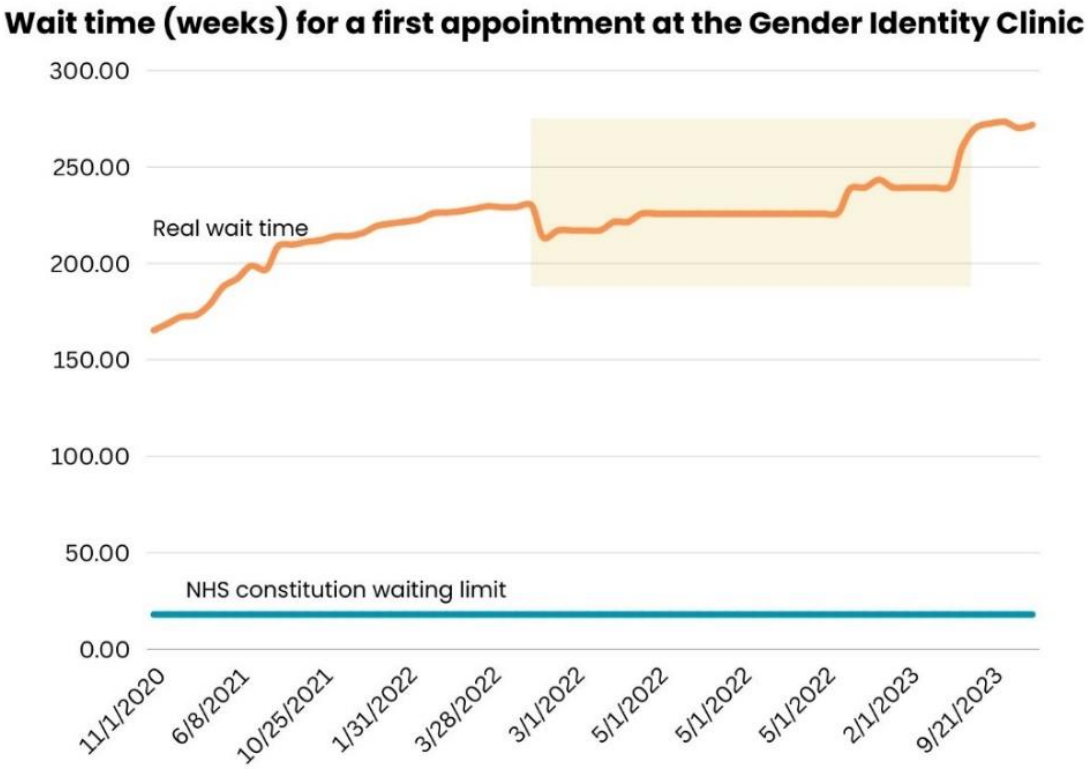
Lesbian, Gay, Bisexual, Transgender and Queer (LGBTQ+) people experience significant health inequalities, which impact their health and their trust in the health system. Many trans people report 'transphobia, stigmatization, ignorance, and refusal of care when seeking health care services.[9] In a recent survey by Stonewall, one in six (16%) trans respondents were refused care by a healthcare service because of being LGBT.[10]

Trans people experience unique inequalities and are even more likely to have a mental health issue compared to members of the broader LGB population.[11]



[9] E. Coleman et al., 'Standards of Care for the Health of Transgender and Gender Diverse People, Version 8', *International Journal of Transgender Health* 23.1 (2022), page 1-258 (56).
[10] Stonewall, *LGBT in Britain: Trans Report* (2018), page 14.
[11] J McNeil et al., *Trans Mental Health Study* (Scottish Transgender Alliance: 2012), page 50.

They also face unique forms of discrimination when accessing services. This included long wait times for **gender dysphoria clinics**, previously known as gender identity clinics. Trans and non-binary residents of Lewisham will usually be referred to the Gender Identity Clinic on Portland Street, where only 14.8% of participants referred after 2017 have been able to attend a first appointment.[12] The waiting time can often exceed 40 months, which is far above the 18-week time limit to provide a first consultation after referral.



There are also difficulties associated with accessing other services, like GP services. More than a third of trans people said they avoided getting treatment due to fears of prejudice.[13] Researchers also often find that an insufficient level of knowledge and training mean that trans and non-binary people often feel like they have to educate their medical providers how to care for them.

[12] Transactual, *Transition Access Survey 2022* (2022), page 46.

[13] London Borough of Lewisham Health and Wellbeing Board, *Transgender Population - Follow up from Lesbian, Gay, Bisexual, Transgender and Queer Plus (LGBTQ+) Joint Strategic Needs Assessment (JSNA) Report* (2023), <https://councilmeetings.lewisham.gov.uk/documents/s110861/Cover%20Report%20Transgender%20Population%20Paper%20for%20July%202023%20HWBB.pdf>, para. 5.

What is available?

There are lots of useful resources for trans and non-binary people in Lewisham. Some of these have been compiled into lists on the Lewisham Council website. Unfortunately, lists are not always up-to-date with changes to resources or projects. Some key charities include:

CliniQ is a holistic clinic and drop in space for the trans* community. They offer 'free counselling, advice and support services and can advise on wide range of well-being issues.'

Spectra is a peer led service for LGBT+ people in London to get support on a variety of issues. They have a series of Trans Services, including a peer advocacy service and resources on self-advocacy.

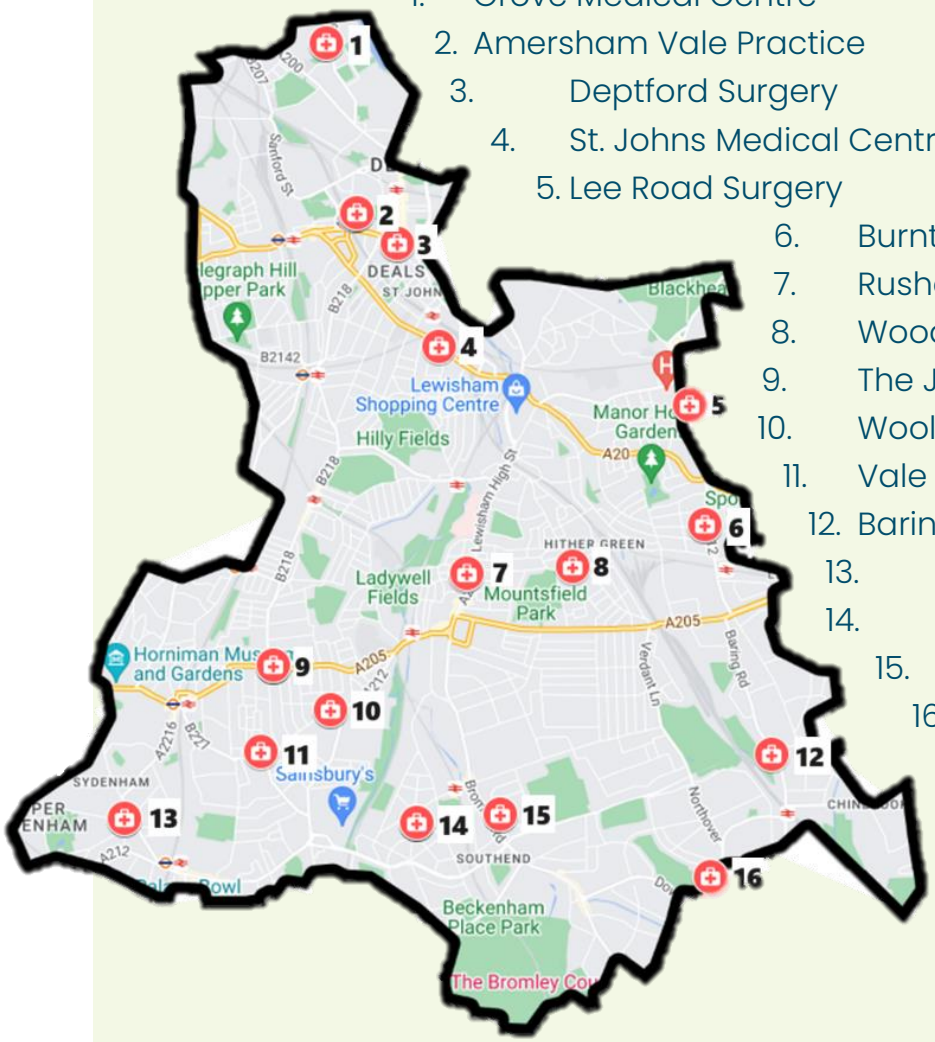
Metro Charity helps LGBT people with a wide range of services, including advocacy, workshops to challenge bullying, mental health support, and sexual health support.

Gendered Intelligence is a trans* run charity aiming to increase 'understandings of gender diversity and improve trans people's quality of life.' They recently launched the Trans Dimension, a community hub that shares organisations and events useful for the gender diverse community.

The Bridge @ Southwark is a primary care clinic for trans and non-binary people. They can offer a variety of services, such as cervical smears, information, signposted and, most often, bridging prescriptions. It is run in collaboration with CliniQ in South Southwark, but accepts patients from other boroughs, including Lewisham.

Lewisham was the first borough to implement the **Pride in Practice** scheme, a training programme founded by the LGBT+ foundation that includes training on addressing gender diverse patients. The LGBT+ foundation provides a map of trained practices which we have compiled here. It is important to note that due to turnover, this does not guarantee that all staff are currently Pride in Practice trained.

The practices below have been trained by December 2023 and according to Lewisham Council over half of all surgeries were accredited by February 2023.



1. Grove Medical Centre
2. Amersham Vale Practice
3. Deptford Surgery
4. St. Johns Medical Centre
5. Lee Road Surgery
6. Burnt Ash Surgery
7. Rushey Green Group Practice
8. Woodlands Health Centre
9. The Jenner Practice
10. Woolstone Medical Practice
11. Vale Medical Centre
12. Baring Road Medical Centre
13. Wells Park Practice
14. Bellingham Green
15. South Lewisham Group
16. Downham Family Medical Practice

Lewisham and South London also has a significant amount of community options, hobby clubs, public spaces, and local venues that support transgender individuals, or are explicitly for the gender diverse community.

What we did

In 2023, the Council suggested that more work was needed to understand the needs of trans and non-binary residents of Lewisham. Given the relatively large trans population in Lewisham, and the fact that other reports by local Healthwatch organisations in Sheffield and Kent found that trans and non-binary people were very unsatisfied with some areas of care, we decided to investigate.[14] [15]

We decided to focus on areas where recommendations were frequently made and where the trans and gender diverse population experienced a high burden. This was GP services, mental health services, sexual health services, and access to gender affirming care at **Gender Dysphoria Clinics**.

We ran one focus group and thirteen one-to-one interviews with trans or non-binary people that either lived in Lewisham or had accessed care in Lewisham in the last two years. These interviews were in depth and semi-structured. They focused around important areas, but interviewees were free to tell stories and stray from the topic guide. We wanted participants to feel like 'experts by experience' and share their insight as they saw it.[16]

In late 2023 we collaborated with members of the trans and non-binary community in Lewisham to help us co-produce questions and be present in interviews to create a more welcoming environment. This helped us avoid 'common pitfalls' of research into trans populations.[17] This was paid work.

The first member of our steering committee had previously accessed our advocacy service and had been keen to collaborate with us. They connected us with useful organisations, consulting on language we were using, and sharing ways they thought our research could benefit the trans and gender diverse community.

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[14] Healthwatch Sheffield, *Experiences of health & care in Sheffield's trans community* (2019).
[15] Healthwatch Kent, *Giving the Trans & Non-Binary community a voice* (2021).
[16] D. Holland et al., 'The Role(s) Transgender Adults Want General Practice to Have in Their Healthcare: A Qualitative Study in Southeast England', *Bulletin of Applied Transgender Studies* 2.3-4 (2023), page 175-194 (175).
[17] Z Marshall et al., 'Trans Research Ethics: Challenges and Recommendations for Change', *Bulletin of Applied Transgender Studies* 1.3-4 (2022), page 187-210.

Recruitment

We used posters and flyers that we shared in GP receptions, libraries, community spaces, LGBT+ friendly spaces. We also had an online advert that was helpfully shared by many gender diverse organisations and in several community WhatsApp groups. Two of our staff members went to local events in person to recruit people, and we also relied on word of mouth as the project progressed.

We used an iterative recruitment strategy to target certain groups we were underrepresenting, since we knew that gender diverse people's experiences can vary based on other parts of their identity.

We did a total of nineteen interviews and managed to recruit people of different ages. We acknowledge that we could have done a better job representing the voices of transgender women and of trans people of colour, but we did have at least one participant representing these groups.

Our Promotional Material

Training

The researchers and the steering committee went through bespoke training from Homeless Link on trauma-informed interviewing approaches and techniques.[18] Talking about potentially traumatic experiences of healthcare could retraumatise our participants and our steering committee members, so we wanted to be prepared.

Interviews

We held our focus groups in person and were kindly allowed to use the quiet room at the LGBT+ Community Centre in Southwark. We asked our participants some questions, but often we learnt the most valuable information when they told us stories about their experiences. All our interviews had a member of our steering committee with lived experience present who acted as a co-interviewer.

Analysis

We thematically analysed our interview transcripts with help from some volunteers who are mentioned in the Acknowledgements section. Below, you can see what we found.

Our report uses a lot of quotes from our participants. This is because we believe in how important these stories are and we believe that, by reading them, service providers and commissioners might be able to see these issues from a new angle.

We also gave our participants pseudonyms that matched their gender identity. You can see these pseudonyms

Funding

This project received additional funding from the Care Quality Commission, as part of their People's Profiles project. The CQC wanted to hear about how particular groups of people access and use healthcare services and what barriers to access there are.

[18] Homeless Link, 'Embedding a Trauma-informed approach' (2023) <https://homeless.org.uk/what-we-do/developing-the-workforce/training-for-organisations/trauma-informed-training-and-consultancy/>.

Our Participants

Age

Harry, 51-year-old trans man.

50

Clara, 44-year-old demigirl.

40

Aspen, 40-year-old non-binary person.

David, 39-year-old trans man.

Jordan, 38-year-old non-binary person.

Sam, 38-year-old nonbinary tranmasc person.

Hassan, 35-year-old trans and genderqueer person.

Finn, 32-year-old transmasculine person.

30

Miles, 29-year-old non-binary person.

Sophie, 27-year-old trans woman.

Riley, 27-year-old non-binary person.

Ash, 25-year-old non-binary person.

Josh, 24-year-old trans man.

Charlie, 23-year-old transmasc nonbinary person.

May, 22-year-old non-binary person.

Morgan, 22-year-old trans person.

Ellis, 20-year-old trans person.

20

What we found

This section of the report is all about what participants told us. We noticed four key areas emerge that caused participants to have **unmet needs**: **identity**, **attitudes**, **services**, and **systems**.

Identity refers to how gender diverse people relate to themselves and how this affects what care they need and want.

Attitudes is about how health professionals treat gender diverse people. Bad attitudes can influence the emotions and safety of patients and can make them less likely to be honest, or to seek out care in the future.

Services refers to how well the services offered met the needs of trans people, how welcoming the environment felt, and how accurate or useful advice from the NHS was. Participants had mixed feelings about services but, generally, GP services and information signposting were usually seen in the most negative light. Many participants had recommendations to improve services for gender diverse users.

Systems refers to the administrative links between services and to the IT systems connecting service users and providers. Participants saw these systems as unfit for purpose for their community. This almost always led to frustration and exasperation, but often also led to much more significant barriers to accessing care.

These issues and **unmet needs** often caused participants to seek out **alternative forms of care**, like doing their own research, seeking knowledge from gender diverse or queer community networks, self-medicating, or (when able) seeking out private care. Evaluating public services can, therefore, be challenging when people's needs are being met through other steams of care.

Finally, the report will look at in depth case studies, to show how care can emotionally affect a gender diverse patient and make them feel.

Identity

Identity was important to a lot of gender diverse people in Lewisham. This included the importance of transitioning to match how they feel. A health provider might view transitioning as a physical, biomedical process that happens to your body, but a service user might instead value the mental and social benefits that come from feeling confident in their body.[19]

> I love my voice as low as it is. I wasn't crazy about the idea of taking hormones, but if they help me achieve my goals, to see myself, [it is worth it]. I didn't even know I would like facial hair; it is not something I planned, but now I can hardly recognise myself when I am clean shaved.
>
> It's complex to understand if you are a cis person, but it's not impossible.
>
> - Harry, 51-year-old trans man

Gender diverse people also told us how other aspects of their identities affected their care in combination with their gender. This included things like being Black, being gay, using a wheelchair, having a chronic health condition, or having a mental illness, among others.

> I have a very definite diagnosis of ADHD, to which I've lost literally decades of my life to not being diagnosed, because nobody even thought about it. Never in my GP appointments has anybody ever even approached any of this stuff, because they're not seeing people holistically.
>
> - Clara, a 44-year-old demigirl.

> Before [identifying as non-binary], it was difficult identifying as a Black female that is not your typical size. I had some really bad experiences that made me not want to access any healthcare services.
>
> If you're a woman, if you're black, if you're gay, if you have a disability, you're at the bottom of society. No one cares about your story, or how you feel.
>
> - Jordan, non-binary person.

[19] Holland et al., 'The Role(s) Transgender Adults Want', page 57.

Sometimes, participants felt that medical staff **over-estimated how important their gender identity was** in comparison to these other factors. Their gender would be brought up in situations that felt irrelevant. In the community, this is sometimes called 'trans broken arm syndrome.'

> I had EDS, and it runs in the family and the rest of my family has diagnosed. And I went to my GP going, 'Hey, I have EDS, and I'm managing it.' The first thing they said was, 'Oh, could it be because you're doing testosterone on your own?' They refused to look into it for me.

- Charlie, 23-year-old transmasc nonbinary person.

> Even when I would go into the doctors like, 'I've sprained an ankle', it would somehow become a whole thing around my transness.

- Sam, 38-year-old nonbinary tranmasc person.

Attitudes

There was not a shared opinion about the attitudes of medical professionals between our participants, but almost all of them could recount negative experiences and different **types of poor attitudes**, **including inconsistencies in levels of understanding,** they encountered while trying to access services.

> It's a roll of the dice. You could get someone fine, you could get someone terrible, and you can't tell until you're in the situation.

- David, 39-year-old trans man.

Participants expressed concern over some medical and administrative staff's **willingness to learn** about gender diverse identities and care. This often meant that they had to spend more time and effort accessing care or did not feel seen or respected. Most of these experiences relates to GP services. Lots of our participants had thoughts about this:

I wouldn't say it was disrespect in terms of being disgusted or anything, but it just feels like there's no space. There's no energy or risk. I can't imagine that they would be particularly interested.

They don't understand trans people. They don't understand pronouns. They don't understand being trans. They have no concept of it really.

I'm nonbinary and keeping having to say that to people that haven't read my file.

The GP had no understanding of specialist referrals, I don't think they'd ever heard of the service before. And they did a physical examination, which is not something that needed to take place. So it just felt very much like they didn't know what was happening.

Quite clearly, most of them don't know what they're doing. They don't want to know what they're doing.

Even when they had done blood tests, the GPs don't know how to interpret them. So, they just do the tests and leave it.

GPs are responsible for educating themselves in areas where they lack knowledge. They don't do that with trans healthcare, they simply don't do it.

I feel like in the actual GP that I used to go to, with the reception staff I didn't feel very respected at times. They didn't respect my time so much.

The psychiatrist basically didn't believe in trans people and therefore refused to see me. He was brief about it, but he couldn't get past it.

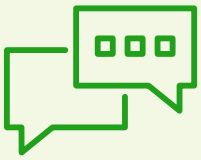
Types of poor attitudes

There were a lot of other ways our participants felt that poor attitudes manifested. Sometimes the **lack of knowledge** of medical professionals made their experiences more challenging or negative. Some participants recounted medical staff asking invasive questions with an inappropriate or **unnecessary level of curiosity**. Attitudes were sometimes cisnormative, which often meant that services were **unfit or inappropriate for non-binary people**.

Some non-binary people and some trans people who did not want to follow a certain transition pathway often felt like they **had to act** in ways that were untrue to themselves in order to receive care. Finally, participants told us how these attitudes made them feel like they were **being discriminated against** because of their gender identity, or because they were looking to undergo transition.

Lack of Knowledge

Firstly, participants felt that there was a lack of knowledge about what it means to be transgender or gender diverse, which caused delays, or caused misunderstandings about what the needs of gender diverse patients. There was also often a lack of knowledge about the patient when they arrived, even though the information was usually on their medical history. There was also a noticeable perceived lack of knowledge about how GP services were meant to interact with specialist services, which is addressed in the section on services.



The kind of the advice [they're] giving is so blanket; it's not tailored to [me] as a person.

If I call to make an appointment, they say, 'Oh, are you making it for your partner?' I'm like, 'No, I'm making it for myself'. Things like that can be really frustrating.

[GPs think] that somehow trans people are so fundamentally different to how they've interpreted other blood tests that they don't know how to interpret them. But I find it a little bit strange that there is that olive branch kind of offered by endocrinologists that are more knowledgeable and they don't take it.

It's a lot of uncertainty.

Although this was mostly in GP services, sexual health services in Lewisham were also mentioned.

The woman who gave me my M-pox vaccine was … really confused for ages… she was looking at me, I guess looking at the criteria of who's eligible. She also left the room for a really long time, like 15 minutes. And I swas just like… "is she coming back?" [laughter], "I don't know!". Then she came back and asked if I was a transsexual, so…

- Hassan, 35-year-old trans and genderqueer person

Unnecessary Level of Curiosity

Four of our participants felt that medical professionals overstepped boundaries by asking questions about their gender identity, or the way they presented themselves, that was not related to them getting the right care.

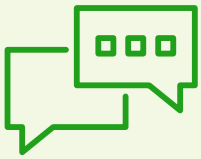
Staff would be looking me up and down and just kind of trying to wrap their head around it.

I have gender affirming piercings in my genital area and they were just like, "Oh my god, how can you even walk with that?" I'm like… "you can't say that!"

The nurse at the GP asked me some pretty insensitive questions and made me way more stressed than I needed to be.

Doctors focus on the wrong thing and misdirect the conversation.

The idea that a surgeon gets to know about what was a therapy point when I was 16 and… it's funny.



Cisnormative attitudes

Cisnormative systems often do not consider that some people identify as non-binary. This can make nonbinary people, or people with other gender identities, feel that the system is not 'made' for them.

> I don't ever discuss my gender identity in a healthcare setting because nobody ever understands it. There's no point in me doing it. I would get no benefit from it. Basically, I never bring up my gender identity and nobody else ever does. I wouldn't get better care if I disclosed what it was. If anything, I might get worse care.

- Clara, a 44-year-old demigirl.

> They are only looking at a blood test for a male profile or a female profile. So, like, if you're non-binary, there are no set markers for you.

- Hassan, 35-year-old trans and genderqueer person.

These normative meant that a lot of transgender and nonbinary people felt like they had to **act in ways that felt untrue to themselves**.

> When I was asking them advice on taking testosterone, putting a feeler out about how I would do it, they told me to just contact your GP and just pretend that you're a trans man, because that is the only way that you'll be taken seriously. Which kind of sucks.

- May, 22-year-old non-binary person.

> I was told: "don't tell anyone you're nonbinary, tell them that you're trans masc or a trans man." It is ridiculous that I had to put a charade.

- Sam, 38-year-old nonbinary tranmasc person.

Discrimination

Some people shared stories of how this poor quality of care made them **feel discriminated against** because of their gender identity, or because they were looking to undergo transition.

> When I had my top surgery and went to get my dressings changed, the nurse at GP surgery was saying that she didn't know how to change the dressings because she hadn't seen this kind of surgery before. I felt like… a nurse changes dressings all the time. It almost feels like if you're trans, there's like bad smell around you… no one wants to come near you because you are high risk, or whatever.

- Finn, 32-year-old transmasculine person.

In another example below, a reception staff informs Sam that they would not receive a letter from the GP that they could use to change their gender marker on their passport. This was because they had not undergone a phalloplasty, or 'bottom surgery.' This is not a requirement for this kind of letter, and it is incorrect to think that all transgender men would seek out this surgery.

> I will never forget, she told me "No, he won't sign off on that because you haven't had the lot done." I was so angry. I said "Excuse me? No, that's not the case. I've been on hormones. I've had an irreversible surgery. I don't need to 'have the lot done.'" I want you to take my form out to him and I want you to ask him to sign it.

- Sam, 38-year-old nonbinary tranmasc person.

These kinds of attitudes all contribute to a poor experience for trans and nonbinary service users when accessing healthcare. A few of our participants directly linked this poor service to stories of themselves or their friends disengaging with services.

> It doesn't make me feel comfortable to actually go and do further research or actually reach out to my GP or like other medical services. I see the surface level stuff and I'm like… this seems inaccessible.

- May, 22-year-old non-binary person.

The example below shows how a system that encourages personal research and self-advocacy, because of uncertainty about the services, can push someone away from seeking care entirely.

> [Some] people go in and they know, I want hormones, I need this, I need that. Whereas if you're not really sure, it's very difficult to navigate, and it's already difficult enough to get therapy and stuff like that. Realistically, what I know that I need is some sort of therapy or counselling from someone that knows about trans issues and that is understanding and that will know how to guide me. But I can't even get that. So in a lot of ways, it's easier to just ignore everything and to push it away.

- Alex, 25-year-old non-binary person.

Positive experiences

Some participants gave examples of better attitudes. If their care was unrelated to their transition, sometimes the best attitude was a neutral one. For example, someone delivering an ultrasound "not batting an eyelid" that their patient identifies as a man, or a physiotherapist at Lewisham hospital being "completely neutral and not having any reaction at all" that their patient is transgender.

Some participants reported positive experiences at Lewisham services. Both Lewisham Hospital and the sexual health services in New Cross were mentioned on more than one occasion for being "nonjudgmental", "accepting", using "inclusive language" and "positive" (though not every experience in Lewisham Hospital was positive). One quote about New Cross points out that, although this was a better experience than GPs, it does not mean that services are perfect:

> It's a low bar but I felt like I wasn't misgendered and that is obviously rare. And unlike most GP receptionists, they seem like they've had training on, like, what trans people need health care wise and social wise.

- Hassan, 35-year-old trans and genderqueer person.

-

Services

A health service could be a local medical practice, a sexual or mental health service, a specialist service, or a number of other things. It was common that our participants did not enjoy going to services, often this was because it did not feel like an **environment** that was welcoming to them.

Many also found it difficult to figure out what help was available to them, because of a lack of **information**. When information was displayed or given to them, it was often **unwelcoming**, **incorrect**, or **did not reflect what they were experiencing**. This was an area where our participants were the most enthusiastic about making **recommendations**.

Environment

Some services did not display any information that made it clear that they would be a welcoming space to LGBT+, or gender diverse individuals.

> In my GP surgery, there are lots of posters about babies and pregnancies, vaccines and flu clinics, but there's no posters or pamphlets about LGBT people.

- Aspen, 40-year-old non-binary person.

Another participant told us why a good waiting room is important:

> If you've had a good experience at a desk in a waiting room, then by the time you get to the doctor, you're probably more likely to be honest with them and feel like you can trust them as well.

- Riley, 27-year-old non-binary person.

Information

One participant told us that it can be difficult to transition because not all people know how to do it. To this person, being able to get information about their options from a doctor would be really helpful and affirming.

> I want to talk to my GP and say, "I think maybe I would want to start testosterone, but I'm not sure what that would actually mean for me, like what the different options are, how much it would be, or if there are hoops that I need to jump through." I would want to be able to have a conversation and be able to self-refer. I would want it to be easy and not really hard. I need those first steps to be simple.

- May, 22-year-old non-binary person.

Unfortunately, many GPs and other health services did not have enough information, which could be confusing, frustrating, and even scary.

> You're expected to know how your body's meant to respond. It feels like you're meant to know which side [of the sex binary] you fall on. I think I'm fairly medically literate, I can do the Google Scholar thing, and I still can't find answers. Should I panic when I get like a sense of dread and a bit of tiredness? Who knows?

- Josh, 24-year-old trans man.

> I wouldn't say that I have really found any information through actual health services to be honest.

- May, 22-year-old non-binary person.

> The advice they're giving is so blanket, it's not tailored to me as a person.

- Aspen, 40-year-old non-binary person.

One participant also felt that the language on the NHS website could be made friendlier, or more accessible.

> The NHS page for testosterone feels like scare mongering. The information is unclear, intimidating to look at, and not really helpful. For hormone treatments, the language they use is scary and alienating and they try to be inclusive, but is it not in a way that actually makes me want to continue researching on

- May, 22-year-old non-binary person.

Incorrect or Outdated Information.

Sometimes, the information people *did* receive was incorrect. This was sometimes due to a lack of understanding about what hormone therapy can do for the bodies and feelings of trans people.

> I genuinely don't think a lot of medical professionals understand what testosterone does? Yeah. Because I feel like it's very stigmatized, and they just kind of assume you get really muscular and angry.

- Josh, 24-year-old trans man.

> [NHS online information] doesn't really acknowledge that some of the things that testosterone does are things that people want. Nowhere in that page does it say, you know, trans people take this under medical guidance for them to feel more affirmed in their gender.

- May, 22-year-old non-binary person.

Sometimes, these examples were more alarming. This included a GP incorrectly implying that hormones are not prescribed in the NHS. Many participants worry about more decision-making being ascribed to GPs under new guidance and saw this as a potentially negative change.

> I'm especially worried now because, in the new young people's gender service guidance, the GPs are basically the main gateway for young people to access that service. I'm so worried about this because it cuts out all those people in the community.

- David, 39-year-old trans man.

Current guidelines say that if a GP feels like they "lack knowledge and experience about the healthcare needs of transgender and gender diverse people," [they should] consider developing [their] competence."[20] These guidelines also say that if a GP feels like they cannot provide appropriate arrangements, they must inform the patient and any specialist involved in a shared care agreement.

Hassan and other participants felt that many GPs "don't do that with trans healthcare, they simply don't do it," and they worry what might happen if GPs are given more agency, with fewer checks on whether they are educated about gender diverse health provision.

[20] General Medical Council, 'Trans Healthcare' (2016) <https://www.gmc-uk.org/professional-standards/ethical-hub/trans-healthcare>.

Feeling upset, angry, or helpless because of poor service

Many participants pointed to the ways a lack of information or lack of education on gender diverse healthcare could make them feel angry, upset, or helpless.

> I've also had a lot of experiences with the receptionist acting like gatekeepers. I was like, 'we haven't scanned for testosterone.' And she was like, 'yeah, yes, I have - this one is testosterone' and pointed on the list. I left and Googled it and it wasn't testosterone, she was just completely lying to me. So I went back in. I was really upset, obviously, and she started shouting at me. And she was just like, 'don't bring your attitude in here!'

- Sophie, 27-year-old trans woman.

Recommendations that our participants had for GP services and information signposting.

Our participants had a few recommendations that might make services look more like May's vision, where gender diverse people might want to go for advice, help, and care. These included an **openness and honesty** about what service providers did and did not know, **a willingness to learn**, and **better information and signposting.**

> If you don't know, say you don't know, tell trans people you don't know which symptoms they should be experiencing, rather than hoping and praying.

- Josh, 24-year-old trans man.

There were lots of ideas about how better information could be provided. One person suggested "having a page that directed you to useful resources." Another suggested a list of "trans friendly GPs", that have passed training or had experience working with trans service users.

Specialist Services

The specialist **Gender Dysphoria Clinic (for adults) and Gender Identity Development Service** (for under 18s) were generally seen in a more positive light, aside from the administrative staff. One participant said they seemed "patronising". Another felt like the administrative staff were "quite dismissive", and "not super affirming". All GDC services are out of borough.

CliniQ and Spectra

Cliniq is a trans led "holistic sexual health, mental health and wellbeing service for all trans people" on Denmark Road. Our participants had only positive things to say about CliniQ, they only wished that they each had a larger capacity.

Sam is a frequent user of CliniQ. The nurses there taught them how to self-inject testosterone. They had the following to say about the service:

> I go to their office, because I trust them to do stuff... It was the most affirming space.
>
> They always sent me home with a bunch of needles and syringes and plasters all the bits I'd need in order to do it myself. That's awesome.

- Sam, 38-year-old nonbinary tranmasc person.

Another participant focused on the fact that CliniQ made them feel safe when they were getting a cervical smear:

> When I went in for my cervical smear, they told me it'll be fine. They said 'I get why you're a little bit nervous about it, but you'll be alright. We'll make sure that it's fine.' I don't think I would have felt that if I had gone to my GP for it.

- Miles, 29-year-old non-binary person.

Spectra is a peer service for queer people, which has a series of trans services. This includes counselling, peer mentoring, health advocacy, social groups, and informative workshops. Only one of our participants had accessed Spectra before but found it a really helpful service.

The only recommendations participants had for these services was that "more people had access to them", or if "there were more".

Hospital services

We heard some stories about Lewisham Hospital. Half the stories we heard were positive and involved a doctor or physiotherapist being "completely okay", or "very friendly". The other two stories we heard involved doctors making our participants feel embarrassed by misgendering them while they were in the A&E department.

I could hear the doctor talking to another doctor, being like, "I don't know what to do... he says he's trans and like, he's had this surgery and that surgery, but not this other surgery' and I was like, you could have just not done it in my earshot!

- David, 39-year-old trans man.

Some of the nurses misgendered me... even though I've been transitioned 15 years at that point."

- Sam, 38-year-old nonbinary tranmasc person.

Systems

Systems refers to the links between services and the IT systems that make them all work. There were some issues that were fundamental and, at times, seemed to be extreme versions of issues that arise elsewhere, like long **wait times** or **poor integration**. Some issues, related to **medical records**, the **lack of transparency**, or the **lack of ownership** for certain patients felt more discriminatory and related to the identity of the participants. The medical system also felt poorly connected to other systems, like the ones to change your name or to edit the gender signifier on your passport.

All these systemic issues meant that our participants often felt they **had to educate medical professionals about what their role in the system was**.

There were some **positive experiences** and our participants acknowledged that the issues were probably exacerbated by **larger funding issues in the NHS**.

Wait times

The wait times are very long to access specialist services for gender diverse people. The most up-to-date data shows that people currently being seen for a first appointment have been waiting for five years. [21] Participants

[21] The Tavistock and Portman NHS Trust, 'Gender Identity Clinic (GIC)' <https://tavistockandportman.nhs.uk/services/gender-identity-clinic-gic/>.

generally understood these longs waiting times and one participant mentioned that they waited for a year, which was "Not long - by trans standards".

It is important to note that the wait time for the first appointment was usually the longest one. When some of our participants began their transition, this was the only way to begin hormone replacement therapy. Today, service users can access hormones through a GP with a bridging prescription.. As a reminder, the backlog to be seen at the London gender dysphoria clinic is currently five years.

Administrative Systems

This wait time was often exacerbated by the fact that not all GPs were willing to prescribe hormones. Participants shared that moving between GPs added to *de facto* wait time and caused more labour for them.

> I've switched to GPs as well to try and kind of find one who might be better. And that's a long process in itself. And like, it's just boring having to do all of this, like admin all the time.
>
> - Ellis, 20-year-old trans person.

> I went to another doctor and finally got the ball rolling and I was able to get sent to the GIC.
>
> - Sam, 38-year-old nonbinary tranmasc person.

In more than one instance, a participant had been told the GP had referred them to a specialist service and had waited for years, only to find out that an error meant the referral had never happened. We go into more detail about this in **our case study on poor service**.

> When I asked my GP to clarify like, Oh, where am I on the waiting list? Because it's been like, what, four years? They were like, Oh, I don't think you there because I changed my name with a deed poll.
>
> - Charlie, 23-year-old transmasc nonbinary person.

This feeling that the administrative system had a lack of transparency was felt by more than one participant.

> So I recently had to call them and be like, Why do you keep declining my hormone blocker? I've paid for this medication that you just keep declining it. Why is that and no one could give me an answer.

- Miles, 29-year-old non-binary person.

Some of the IT systems felt unfit for purpose for nonbinary people because they ask for a gender upon arrival, even if it feels unrelated to what care is being sought. To some, it can feel like a barrier that makes the experience less simple.

> You log in, you put your name and your date of birth in, and then it comes up with your gender, male or female. In many other forms of life there's another option, a of tick box. But in medical settings, there just isn't. So go in already having had to lie, essentially. You've had to make some kind of concession in your own identity before you enter the door. And then, do you then feel comfortable to correct that with the doctor that you see when you first get in? Does it matter?

- Riley, non-binary person.

Medical Records

Changing your gender marker on your medical records is a way that gender diverse people can make sure that their marker reflects the gender they live as. It can mean they are misgendered less by staff, for example,

However, some of our participants ran into issues when they changed their gender markers. It sometimes meant they were not called up for cervical smears. Woolstone Practice offers a service where they can call you up for cervical smears if you are a trans man or nonbinary person with a cervix. This shows that the some of the difficulties caused by medical records are not unavoidable, or fundamental.

Gender Markers

There is an issue where changing the gender marker of a patient can sometimes create a new NHS profile and NHS number, which 'locks' the original account and means that the service user does not get updates about their healthcare, is not invited for regular tests or screening, and can find it very difficult to access their care records. We noted that our participants were advised by the GIC, Spectra, and CliniQ that this was a known issue that continues to occur with people's records. The fact that this

issue continues to reoccur is incredibly alarming and often results in an incredibly long and frustrating experience.

On the next page is a case study from our participant Clara, that details some of the difficulties faces. However, it is alarming that our of our sample size of 18, this had happened to two people, and three more had heard of this from a friend or a specialist service.

> And when it came to the point that like, I was trying to access my medical record because trans plus told me that if I change my gender marker, I'll get issued a new NHS number, and they said basically, like a lot of people find that their medical goes missing, and that I should access the medical record now.

- Finn, 32-year-old transmasculine person.

Gender Marker Case Study

Also, with the whole name change thing, so a [previous partner] tried three times to get her name changed over the course of just over a year and did not make any progress until I sent them an email explaining the content of the patients and records website (which comes up when you Google, it's not hard).

That's the only reason I know it because I just Googled it. I didn't do it through some kind of special magic trick, I just Googled it and I told them how to do it according to what they say on the website, and then they messed it up.

This meant that she had one [locked] empty record and one record with data on and that meant that she didn't get her COVID Vaccinations for several months after she was eligible for it, despite the fact she was working as a bus driver and was so worried about catching COVID.

It took a while to understand what was going on because they kept saying 'There's no information on your record'. She tried to change GP surgeries and because of what happened and when she changed GP surgeries with the NHS number that didn't have information attached to it, they were just like nonplussed and we were nonplussed and then basically she disengaged from any sort of health care.

.Lack of Integration

Integration is when services work well together and feel like one coherent system. Lots of our participants felt that the communication between services was very poor and affected their wait times and ability to access care.

I have never gotten care in time. It's always as a result [being told], 'oh, we need to review you being on testosterone or you being gender diverse…'

I'm sure everyone has said this, but it was a horrifically unjoined up.

I couldn't get an appointment at my GP surgery. And then when I tried to get it at my GP surgery, they were like 'you need to be assessed because you haven't had hormone blockers for three months'. I was like, 'Well, I've had it at this other place. Do they not send the records on to you?' And they were like, 'No'.

GPs always say, 'I can't find it here. It's not it's not on your record'. That is one thing that is still hugely affecting my health care to this day.

The assumption [between services] seems to be not sharing.

It shouldn't be on me as the patient to have to explain over and over, every three months, what my medication is for. If they just had taken five minutes to scan my record they would know where I am coming from

Lack of ownership

Some participants that had to move between GPs often to get care found the process exhausting. Some of our participants told us about other feelings this caused. It made them feel like the system did not care, like it was trying to shut them out, because they were a problem patient, or because they could not be bothered to deal with what they felt is a 'complex case'.

> Well, originally, I wasn't seen because I was trans, they lost my referral four times because they see that I'm trans on my record and they don't want to deal with that.
>
> It makes you feel a bit gross and like no one wants to talk to you. We're just being passed from service to service.

- Finn, 32-year-old transmasculine person.

> They're treating [my transition] like it's a treatment plan for like a broken leg where like, your leg is broken, it sets, and then you have six sessions of physio and it's fine, then if you need anything, because it starts hurting again, come back. But. I will always be trans and the plan is that I will always be on cross sex hormones, I will always be on this treatment regime that they prescribed, but they don't feel any ownership over it.

- Josh, 24-year-old trans man.

> I was living with three other people at the same address and we could see the GP surgery from my house.
>
> We were all registered there, but they sent a letter to [my transgender housemate] saying that deregistered her because she was out of area. Nothing about her address had changed, and it's clearly within the boundary. They threw her off because they didn't want to deal with her.

- Clara, a 44-year-old demigirl.

The Wider System

Despite how difficult, opaque, and inaccessible some participants found the medical system, some noted that engaging with it was the only way they would be able to make gender affirming changes to their other records, like their legal name, their passport, or their application for a gender recognition certificate.

> [Health professionals] need to be more understanding about disparities between people's access to gender affirming stuff... it was hard for me to change my gender marker because I had to show ID.

- Morgan, 22-year-old trans person.

> I've been applying for my gender recognition certificate. They said it would take eight weeks, but it ended up taking four months, so I missed deadline after deadline.
>
> They didn't communicate with me when it was ready. They told me they would call me when it was done and then they didn't.

- Miles, 29-year-old non-binary person.

Finn was aware of the known issue that some people that changed their gender markers could be locked out of their health records. This made Finn worried about the implications of changing their name and the effect that might have on their medical records.

> It genuinely took months of pushing just to access to medical record, which means that I've delayed changing my name by deed poll for like a year because I was scared that if I changed my name by deed poll, and then that links to my GP you know, if I ended up getting a new NHS number...

- Finn, 32-year-old transmasculine person.

Having to educate medical professionals

Because of these challenges and because participants often felt compelled to do their own research, because information was not available, this meant that they often felt like they needed to educate medical professionals in order to receive care.

This issue was particularly apparent in GP surgeries, with doctors and receptionist staff. Some of our participants felt like they spent a lot of time "explaining to their GP, what they should be doing them", because "GPs were just generally useless". Charlie felt that "all of the conversations they had with a GP, were just him telling them what the process should be." Generally, this would sharply decrease how much faith a gender diverse person had in the health care system.

I remember this one call with a nurse describing to her what a bridging prescription is, and why I should get one and that was so viscerally disturbing that my nurse - who should talk to me about my medication - didn't know what the results even could be.

- Charlie, 23-year-old transmasc nonbinary person.

Without fail, every three months, I have to phone up my GP two weeks in advance to say, 'Hello, I have a hormone blocker that I need to get done, you're the one who provides that' and every time they go, 'What are you booking in for? What's that for? Do we prescribe that medication for you?'

I've been at this GP surgery for like three years, and I've been having this done consistently every three months. I know the NHS is busy, but also it's right there in my notes! It's exhausting.

- Miles, 29-year-old non-binary person.

I'm always having to educate the person and I shouldn't be having to educate someone else. I shouldn't feel a responsibility as a vocal and articulate member of the community that I have to educate doctors for when the next trans person comes in either.

- Finn, 32-year-old transmasculine person.

They're only doing the tests because I'm on this repeat prescription of testosterone and every so often they receive a letter from the GIC with a leaflet that says, 'Oh, by the way, if this person is on hormones, you must make sure you're checking their bloods regularly and if you've got any questions, contact us', but they don't. I've asked them 'are these bloods, okay? Is this normal?' and they don't know. I have tried to tell them that they can contact the GIC, but they just never take any action.

- David, 39-year-old trans man.

I called them to get my bloods done because of my hormones and said 'This is what's happening. I need to test this. These are the things that you test' and when I walked all the way there to pick up the results, it just was testing testosterone. I need to test like these six different markers, but they wouldn't listen to me on the phone.

- Clara, a 44-year-old demigirl.

I felt like I was just going in there saying, 'You need to write this letter, you need to write this exact thing. This is what you write, please make sure you write this.' They would do it, but you didn't get any impression that they had any notion of what it was.

- Sam, 38-year-old nonbinary tranmasc person.

Poor Service Case Study

The following testimony from one of our study participants says a lot about different challenges with the current system.

I went to an organization called Spectra and they found out that my GP had said that I'd been referred to the Tavistock gender clinic three years prior, but it turned out that Tavistock had no record of me.

That was stressful, but then they helped me to figure out that I was eligible for the pilot scheme at trans plus. That was something I'd heard of that I didn't think I was eligible for, but they helped me to plead my case that it wasn't my fault that the GP had said that they would refer and then they didn't, and luckily trans plus were like very understanding.

Since I've been with trans plus, it's been smooth sailing, but I also had a GP in Lewisham who I think went above and beyond to help as well with that.

I'd gone to my GP as in the Lewisham Care Partnership and made an online query: "do you have any staff that are good with 'trans stuff', or have experience with trans clients? They recommended someone and it wasn't like he was mad clued up. I feel like they just recommended him because he was relatively young. But you know, he tried his best and he wasn't perfect, but I do feel that without him I wouldn't have got where I got.

I wanted to have fertility preservation and this GP did a very persuasive referral and managed to get that fully funded. They were also liaising with the Tavistock clinic and trying to help that way, too.

I finally had a GP that I could go to about gender affirming care. Disappointingly, though, when I went to go back, he had left, which shows the lack of continuity of care. Now if I have an issue related to gender, I always see a different doctor; I would just have no idea where to go. I think that's a bit hard, because you don't know who's going to be transphobic and who isn't.

I'm terrified that I'm going to need a GP and that they won't be understanding, and I don't know who I'd speak to. That is something in Lewisham that I'm finding quite hard.

- Finn, 32-year-old transmasculine person.

Positive experiences

Although there were issues, people who had lived elsewhere in London had said they found it easier to get general appointments once they moved into the borough. Lewisham felt more "streamlined and effective" than Hillingdon in West London. The Waldron Health Clinic in Amersham Vale, that provides sexual health services, was praised by two participants that found it easy and quick to get an appointment there.

A couple of participants noted that their GP had referred them for a first appointment with the GDC very quickly and, although the wait time was long, they had been put "straight on the list with no problems".

Pride in Practice Case Study

Though most participants were not aware of Pride in Practice, one of our steering committee members , through working with our project, found out about the scheme. They switched their GP to Woolstone Practice, an accredited GP service and had an overwhelmingly positive experience:

I had no idea pride in practice existed. And when I saw it in the document that was being shared as part of [this project's] steering group stuff. I was like, Excuse me, what is this?

There were obviously some in Lewisham, so I wondered if there were any near me. I didn't want to switch GP before, because I had so many things going on and I though, just stick with it. The pride and practice GP though was fifteen minutes' walk from me!

So I went there, I was like, Okay, I'm going to move doctors to you and they were incredible. First of all, they were like, 'Is there a name you would prefer we use for you. Amazing. So I had that really great interaction with the person I signed up with.

Then I had my first appointment with them and it was a phone appointment and it was about a repeat prescription thing that I needed to talk through with them, but they were like, 'Oh, while we have got you, let's just go through a few things, because it's our first time talking to you as a patient. They said,

'I can see that you're accessing HRT, you know, were more than happy to do your injections for you here, it's fine, if you'd rather not, but that's an option for you here. They also asked when my last cervix check was and said 'we actually have a service here where we can remind you. So we will set up a reminder, and then send it to you to remind you that needs to be done.'

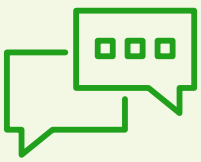
They were just really asking all the right questions and using the right language. I remember, I got off the phone with them and I voicenoted my mate to say: 'I had just a good doctor appointment, where I left feeling affirmed and also they actually cared about my health!'

I went back and the staff on reception are lovely.

Despite the fact that I have to access the GPU a lot, I probably would have accessed them more if it wasn't so frustrating.

Wider Issues

Our participants, when they talked about systemic issues, also reminded us that the NHS and by extension many local and specialist services, were overworked and underfunded. Supply chain issues caused by Brexit and the COVID-19 pandemic were also mentioned, as they caused long delays for 'non-urgent' blood testing.[22]



It feels like a huge, big-picture dream, because of because the state of the NHS

There's like a sense that there's not a lot of money going around.

The NHS is understaffed and there's not enough funding.

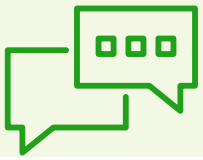
Throughout the pandemic there was long period where they just never did any blood tests.

[22] Rachel Schraer, 'Patients' access to vital NHS tests delayed by warehouse failure' (7 October 2020), BBC News <https://www.bbc.co.uk/news/health-54435226>.

My surgery is like really oversubscribed, overworked and the GPs are overworked.

I can see how the system is just so like overburdened at the moment.

You know how hard it is to call at any hospital department? So many times there's just no answer.



Alternative forms of care

In general, the current system seems to leave gender diverse service users with a lot of unmet needs. This often means that people seek out other alternative forms of care. Sometimes this means making the traditional medical process simpler by **self-educating or advocating**, through a service like Spectra, or by self-advocating. Sometimes this means enmeshing themselves in gender diverse spaces and **communities,** for emotional support. Some people access **private care** in order to avoid a system that causes them difficulty and finally, some access **DIY care** for the same reason.

Self-Educating

The lack of a consistent health service means that trans or non-binary people supplement their care with education that they have independently sought out. As one participant noted, "If I didn't come in knowing what I needed, I don't think I would find any consultation."

We heard from one of our participants who already had a chronic care condition, that was used to advocating for themselves in healthcare settings, that this previous knowledge helped prepare them to navigate the healthcare system when they wanted to transition. They noted that this was exhausting and they would rather not have to do it.

Community

Self-educating was sometimes done independently, particularly by one participant that mentioned that they were less 'enmeshed' in the trans community. Other participants got their information by asking other gender diverse people or by accruing experience naturally by being in certain spaces.

We heard a lot of about in person meet ups to play sports or hang out, community WhatsApp groups, or the use of the queer dating and community app Lex.

> There's this queer app called Lex with a real community feel on there. I would look through the testosterone tags, or all posts of people asking similar questions to mine.

- May, 22-year-old non-binary person.

> Through groups on WhatsApp, I found out about other people's experiences, and then I found out about the GIC.

- Morgan, 22-year-old trans person.

> It's important for me to be able to talk to other non-binary people, being black as well.

- Jordan, non-binary person.

Environment

Learning from peers was not only seen as helpful, but also as empowering. Some felt more confident, safer, or just more able to explore their own identity without worrying that the things they say might impact their access to health services.

> My first trans night that I went to, [I found that] there's a culture of being more liberated and talking about their experiences with different hormones.

- Morgan, 22-year-old trans person.

> I'm trying to sort of branch out and meet more gender diverse people, to try and steal other people's confidence that live their lives authentically and be like, Oh, okay, cool. I can do it too.

- Aspen, 40-year-old non-binary person.

Private care

Our participants that did seek private care pointed to the failure of the NHS system as a motivation for why they did this.

The word 'lucky' was used on multiple occasions to communicate that participants understood that not every person is able to take this path and that many have to rely on mutual aid, mainly from the gender diverse community, to receive care.

> I'm actually thinking about actually paying for privatization or something this year. Just to sort of not have to wade through.

- Aspen, 40-year-old non-binary person.

> This private care was done kind of directly because of an unmet need in the public health care system.

- Sam, 38-year-old nonbinary tranmasc person.

'DIY' care

DIY or 'Do-It-Yourself' care was common between our participants and was also often framed as a reaction to not having their care needs met. This could be because they were unable to get a prescription, or because long wait times meant they began keeping a stockpile or hormones.

One example brough up was bodybuilding forums or reddit communities, where transmasculine people would go. This was either to find information about which sellers on the grey and black market were reputable, or to directly buy from people who also distributed testosterone to people (usually cisgender men) who used it for bodybuilding.

Although these can be uneasy alliances or potentially dangerous situation for gender diverse people, it is again important that this was usually framed as a last-resort access gender affirming care that occurs *because* of challenges arising in the public health system.

> Because of [poor service], I ended up having to go to the GP six times to get my blood test results, by which time I ran out of hormones. So at this point, I now use the grey market to buy spare hormones, because I know this sort of stuff is likely to happen. So I have a stockpile now, because of their failure.

- Sophie, 27-year-old trans woman.

-

> I would tend to do what a friend of mine did, which was going to the local gym and buying it from the gym bros. I'm not the only person I know who does that. Yeah, you know, there's plenty of people who are accessing hormones through buying it off dudes in gyms.

- Sam, 38-year-old nonbinary tranmasc person.

> Some people have shown others how to inject, because there's a lot of people who need their injection done by someone else and their GP won't get that [sorted], even if they have a bridging prescription or even if they have an actual prescription.

- Hassan, 35-year-old trans and genderqueer person.

These are not discreet categories of alternative care. One participant volunteered with a community group that educated, offered peer-education on DIY care, and was a community. This is like cliniQ, which is a 'holistic' service.

What we Recommend

Summary of Recommendations Flowchart

Staff

1. Train health professionals.

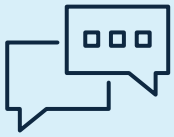
2. Incentivise health professionals.

Services

3. Make existing care services more inclusive.

4. Expand services that work.

Signposting



5. Improve and increase signposting.

Improving

6. Conduct more research into additionally marginalised communities.

Recommendation 1: Increase quality and quantity of training opportunities for health professionals.

Recommendation 1.1: Healthcare professionals should receive **training** on gender identities and gender identity medicine.

We think Pride and Practice, a program founded by the LGBT+ Foundation, is a good option.

Pride in Practice is a national scheme that teaches primary care providers about LGBT+ people and their health needs. It is provided by the LGBT+ foundation.

The Integrated Care System should offer funding to primary care practices for them to take the training. We would like primary clinics that are less willing to volunteer for this scheme to be encouraged.

Recommendation 1.2: Services **retain** their resources from training sessions and implement training for new staff that join.

Continuation of training through staff turnover helps to maintain quality. The health service providers we spoke to could have had more robust systems in place for how they would do this.

Recommendation 1.3: Primary care health professionals should **understand their role** in shared care agreements.

Many of our participants had to explain to primary care services what their role in a shared care agreement was or chase primary services that misplaced incoming material or did not send outgoing material to specialist services.

Primary services were not always the party at fault, but the relationship should be consistent and reliable from the patient's perspective.

A **shared care agreement** is an agreement between a Gender Dysphoria Clinic and a GP, or a private care provider. The clinic will ask the other provider to take responsibility for blood tests and prescribing, including prescribing hormones.

Recommendation 1.4: Secondary care services **consult** with trans-led services.

CliniQ has a history of working with secondary care service in Lewisham and neighbouring boroughs. Our participants saw their partnership with King's College Hospital positively. Moreover, CliniQ have told us they are open to similar additional projects.

We think they might be a good point of contact for secondary services looking to develop or expand their gender identity medicine training programs.

CliniQ is a holistic clinic and drop in space for the trans* community. They offer 'free counselling, advice and support services and can advise on wide range of well-being issues.'

Recommendation 2: Health professionals and services should be incentivised and supported.

Recommendation 2.1: Services should be **aware** of the ongoing support offered from a Pride in Practice manager after the session.

When a service receives Pride in Practice training, they have a line on contact available with the LGBT+ foundation for a period after. This opportunity should be properly used to set up lasting programs.

Recommendation 2.2: An Extended Role qualification in gender identity medicine could be **developed and offered**.

Service commissioners can determine the need for General Practitioner with Extended Role (GPwER) positions and GPs planning to deliver a service as a GPwER are advised to establish requirements with the relevant employer and service commissioner.

a. We recommend that commissioners should consider whether this is required in Lewisham.
b. We recommend that GPs considering an extended role in Gender Identity Medicine should get in contact with us.

Recommendation 2.3: Central bodies should be **checking** in with services to support them.

a. The SEL ICS should be proactively checking in with services to make sure staff are supported to do their best. This includes encouraging and incentivising practices to take up training opportunities.
b. Lewisham Health and Care Partnership should also proactively support services in its network to take up training opportunities, maintain quality, and improve their services in line with our recommendations.

Recommendation 3: Make Existing Care Services More Inclusive.

Recommendation 3.1: Reconsider check-in software that requires inputting a binary gender upon arrival.

The Health and Care LGBTQ+ Inclusion Framework and Pride in Practice recommend that cisgender is not considered the default.[23] [24]

Some of our non-binary participants noted that answering this question before they can check in can feel like a barrier.

> You've had to make some kind of concession in your own identity before you enter the door. And then, do you then feel comfortable to correct that with the doctor that you see when you first get in? - Riley, non-binary person

Recommendation 3.2: Use the pronouns and preferred name you have on someone's file.

It can be an easy mistake to not check this information, but our participants noted that when it happens it can be uncomfortable, awkward, or difficult.

Staff should be allowed or incentivised to show their own pronouns or allyship in emails and on personal ID badges on lanyard badges.

[23] NHS Confederation, *Health and Care LGBTQ+ Inclusion Framework* (2022) <https://www.nhsconfed.org/system/files/2022-10/Health-and-Care-LGBTQ%2B-Inclusion-Framework.pdf>.

[24] *Ibid.*

Recommendation 3.3: A mixed media approach should be taken on by service providers to **engage** with trans and non-binary people. Service should provide and display materials relevant to the trans and non-binary community.

> In my GP surgery, there are lots of posters about babies and pregnancies, vaccines and flu clinics, but there's no posters or pamphlets about LGBT people - Aspen, 40-year-old non-binary person

Providing this information in a waiting room, reception, website or social media channel demonstrates an awareness of trans and non-binary people and their health needs.

CliniQ display flyers about sexual health, HPV testing, and cancer screening for trans and gender diverse patients. If services feel like they want additional resources, this would be a good place to enquire.

Recommendation 3.4: Services need to be **accountable** for their trans and non-binary patients.

Services should be accountable for the care of their patients so that trans or non-binary people do not feel 'passed around', like some of our participants did.

> It almost feels like if you're trans, there's like bad smell around you... no one wants to come near you because you are high risk... - Finn, 32-year old transmasculine person

Primary care providers should be aware of things they can do without involving specialist services, like signing a letter that allows someone to change their name or offer a hormone bridging prescription.

4. Expand services that work.

Recommendation 4.1: Consider supporting **The Bridge @ Southwark** to expand their services into Lewisham.

The Bridge @ Southwark is a primary clinic for trans and non-binary people that runs one evening a month and provides non-specialist primary care services for trans and non-binary people.

The Bridge @ Southwark has a significantly lower wait times than specialist services, costs significantly less, and we think it is an effective addition to the primary care system.[25] Commissioners should communicate with them and consider supporting them in their efforts to expand into Lewisham. Healthwatch Lewisham can facilitate this contact.

Recommendation 4.2: Consider **supporting** additional effective services for the trans and non-binary community.

Other innovative, effective services should be sought out and considered for expansion. Healthwatch Lewisham could work with Healthwatch England and other local branches to identity other kinds of services that are working well.

[25] Stephens, R, *Supporting Transgender and Gender Non-Conforming Patients to Access Healthcare*, (2023), <https://www.nhsconfed.org/articles/supporting-transgender-and-gender-non-conforming-patients-access-healthcare>.

5. Improve and Increase Signposting

Recommendation 5.1: The information from existing guides would be well **placed on a centralised site**, with GPs, and with local community groups.

Services should have available physical written materials like cards, leaflets, brochures and posters available. Providing not only trans and non-binary people with relevant signposting information but also for the staff caring for them.

Recommendation 5.2 GPs should display that they are an accredited pride in practice service.

If a service has completed Pride in Practice training, this should be displayed clearly in person and on their website.

If a service has not completed Pride in Practice training, there should at least be some other resources displayed in waiting rooms.

Recommendation 5.3: Service users should be made more aware of Pride in Practice.

Our participants found the Pride in Practice map very useful once we made them aware of it. We would love the LGBT+ Foundation to make more substantial use of this great resource.

6. Conduct more research into additionally marginalised communities

6.1: Additionally marginalised groups should be built into the recruitment method at the **earliest possible stage**.

This is to prevent the failure of not recognising additionally marginalised groups of the trans and non-binary community and the consequence of them becoming further marginalised.[26]

> If you're a woman, if you're black, if you're gay, if you have a disability, you're at the bottom of society. No one cares about your story, or how you feel – Jordan, 38-year old non-binary person.

Lewisham is a highly diverse borough of London and with an over-16 population whose gender identity differs from the sex they were born with being double than the national average. Improvements include researching more into gender identity (of transwomen), ethnicity and disability. Moreover, a larger sample size needs to be done to further this research to understand the inequalities faced by additionally marginalised trans and non-binary groups.

[26] Stephens, R, *Supporting Transgender and Gender Non-Conforming Patients to Access Healthcare,* (2023), <https://www.nhsconfed.org/articles/supporting-transgender-and-gender-non-conforming-patients-access-healthcare>, Page 33.

Final Words

Michelle, the founder of CliniQ recently spoke at a panel that we attended. She said that even though trans and non-binary people experience a lot of difficulty and discrimination accessing health services, it is important it is to focus on the hopeful stories and positive connections.

We hope that our recommendations can provide evidence on what unmet needs trans and non-binary people have in Lewisham and which organisations can be consulted and collaborated with to meet these needs. We hope that, soon, everyone can feel totally safe and happy to be who they are without judgement or fear in Lewisham.

Acknowledgements

This project received additional funding from the Care Quality Commission. The report was completed by Jack Burnett, Gabrielle Alfieri and Deneesha James. We are very grateful for the volunteers that helped us as well as our interns: Caoimhe Lyons, Subiksha Raghuram, and Rhys Brown-Mantle.

This report was greatly improved by the experience and input of our steering committee, Jack Emsden, Maria Mautino, and Jack Wakely.

Many organisations generously helped us by promoting our project, letting us attend their events, and welcoming us into their spaces. We are particularly grateful to the LGBT+ Community Centre, who let us use their quiet room to hold our interviews and to Homeless Link, who provided excellent training on taking a trauma-informed approach.

We are also grateful to Transactual, CliniQ, Spectra, The Bridge @ Southwark, LGBT+ Foundation, the SEL ICS and local primary care services, who shaved invaluable information with us.

Most of all, we are grateful to our participants for sharing their stories.

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Appendix

APPENDIX A: Interview Protocol

Research Title: Trans* and Non-Binary Health Experiences in Lewisham

Site of Research: Lewisham, UK.

Interviewers: Jack Emsden, Jack Wakely, Maria Mautino

Researchers: Gabrielle Alfieri (gabrielle@healthwatchlewisham.co.uk), Jack Burnett (jack@healthwatchlewisham.co.uk)

Page 1: Expectations. Page 2: Pre-Interview. Page 3: Interview. Page 4: FAQ.

Expectations:

We are doing guided interviews. The questions are to help direct the participants, but our main priority is to hear their experiences. We want the interview to feel like a conversation and we want the participants to understand that they are the experts of their own experience.

Interviewers will not push questions if the participants do not want to answer.

Interviewers should be able to notice signs that the participants are uncomfortable and address this appropriately (particularly after the training).

Interviewers should be attentive and be listening to what the participants are saying. This is to demonstrate empathy and to not have things brought up that were already mentioned.

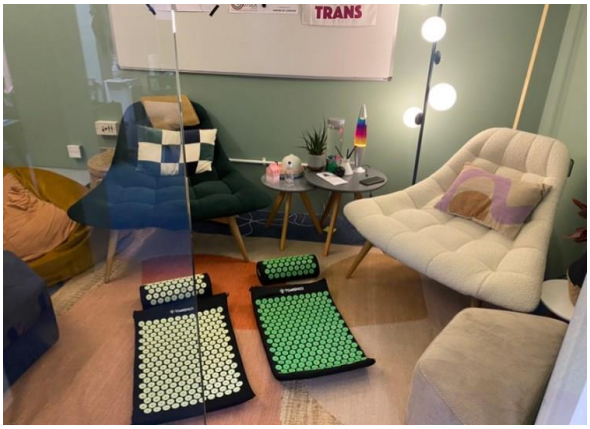
Researchers should feel confident explaining the purpose and remit of the research.

Environment:

The interviews are within the LGBTQ+ Community Centre.

Refreshments are available from us.

The interviews will take place in the 'quiet room'. This picture is of a comparable place.



Pre-Interview: 15 minutes

Pre-Interview conversation: 7 minutes

- Thank them for coming.
- Thank them for agreeing to take part in the research.
- Explain again what the research is, why we are conducting it, and give them an opportunity to ask questions.
    - (mainly for Jack B and Gaby, but steering committee members are of course able to give some context about their own work, or the nature of their role in the project).
- Emphasize that there are no 'right' or 'wrong' answers and that they are the 'experts by experience'.

Consent & structure: 7 minutes

- Give out the information sheets.
    - (participants should have already seen these)
- Give out the topic sheets.
    - (These will also already have been seen)
    - Explain the nature of semi-structured. That it is a guide, not an agenda. That we may ask again about certain things, but that does not mean you absolutely have to give an answer.
- Give out the consent sheets.
    - Receive consent for interviewing and for the recording for the interview.

Interview: 45 minutes

Beginning:

- Go around the circle and collecting names and pronouns.
    - (Researchers, steering committee, and participants)
- Quantify what services people have used, what kind, and how often.
    - We don't need an exact number of how many times, just a relative frequency.
- Researchers will bring a signposting sheet.

Middle:

Interview should flow and follow a rough 'plot'.

This involves of pre-care (signposting, referral, access), care (examples, evaluation), and post-care (impact of care, recommendations, other forms of care)

- Gender Affirming Care:
    - Signposting, Access
    - Examples of care, Evaluating examples
    - Impact, recommendations
    - Non-health service GAC
- All Other Health Services
    - Impact of gender identity
    - Staff understanding of GAC.
    - Staff understanding of gender diverse identities (clinical and admin)
    - Staff respect (clinical and admin)
    - Recommendations

End:

- Wrap up when there is five minutes left.
- Thank them again for participating.
- Remind participants that they will receive a copy of the finished project.

Post interview:

This can be an iterative process. Something learnt on the Thursday interview could inform the Friday Interview. Something learnt at either interview could inform the 121s. A short conversation between researchers and the steering committee after the interview, or by text, would be helpful.

Questions we might be asked:

(Think about: who is this question for? EG: Remit of Healthwatch or signposting is for researchers. Steering committee may be able to speak to experience – but are not expected to and should not feel like they have to).

How can I trust you to tell you my story?

Will the people I name get in trouble?

Will I get in trouble?

What is being done about these issues?

I want to talk more about these experiences with someone, where can I go?

Why are you recording me? Do you have to?

What gender affirming care is there in Lewisham?

What is Healthwatch, who works for Healthwatch?

APPENDIX B: Interview Topic Guide

Research Title: Trans* and Non-Binary Health Experiences in Lewisham

Site of Research: Lewisham, UK.

Interviewers: Jack Emsden, Jack Wakely, Maria Mautino, Jack Burnett, Gaby Alfieri

Researchers: Gabrielle Alfieri (gabrielle@healthwatchlewisham.co.uk), Jack Burnett (jack@healthwatchlewisham.co.uk)

Introduction:

Participants and interviewers have the opportunity to share names and pronouns, if they want to. They can share why they became involved in the project.

Gender affirming care:

How did you find out what options were available to you?

How did you go about seeking out these options?

How easy or difficult was this?

What examples of gender affirming care have you received in Lewisham, or received from referrals in Lewisham?

How easy was it to receive this care after you were referred?

How has this care affected your health?

Do you have any recommendations to improve this process?

What examples of gender affirming care have you received outside of health services? This could include self-medication, the impact of community, or doing personal research. (As a reminder, things you say during this interview will not influence how much support you will receive in the future from health services)

All services:

How does your gender identity come up at GP services, mental health services, or sexual health services?

How does it affect the speed or quality of your care?

What level of understanding of gender diversity have the administrative staff and pclinical staff had in Lewisham?

How respected have you felt in healthcare settings?

How is this different between administrative and clinical staff?

Is there an example where you think healthcare professionals have had a good attitude, or have showed good understanding?

What do you need from health services?

How could Lewisham health services be made more inclusive and accessible to trans and nonbinary community members?

Interview questions (closing questions):

In the past two year, which of the following services have you used: GP, mental health, or sexual health services?

Where have you received these services (borough, facility/surgery, etc.)?

How frequently have you sought out these kinds of services

APPENDIX C: Participant Consent Sheet

Research Title: Trans* and Non-Binary Health Experiences in Lewisham

Site of Research: Lewisham, UK.

Interviewers: Jack Emsden, Jack Wakely, Maria Mautino, Jack Burnett, Gaby Alfieri

Researchers: Gabrielle Alfieri (gabrielle@healthwatchlewisham.co.uk), Jack Burnett (jack@healthwatchlewisham.co.uk)

	Yes	No
I have read and understood the study information about the project. I have been able to ask questions about the project and my questions have been answered to my satisfaction.		
I consent to be a participant in this project and understand that I can refuse to answer questions and withdraw from the study at any time, without having to give a reason.		
I understand that information I provide will be used for a published report		
I agree that my information can be quoted in research outputs.		
I understand that any personal information that can identify me, such as my name or where I live, will not be shared beyond the project team.		
I give permission for the information that I provide to be archived and re-used.		

Name of Participant [IN CAPITALS]:

Signature: Date:

Name of Researcher:

I confirm that all the information relating to this research was provided prior to consent:

Signature: Date:

APPENDIX D: Participant Information Sheet

Research Title: Trans* and Non-Binary Health Experiences in Lewisham

Site of Research: Lewisham, UK.

Interviewers: Jack Emsden, Jack Wakely, Maria Mautino, Jack Burnett, Gaby Alfieri

Researchers: Gabrielle Alfieri (gabrielle@healthwatchlewisham.co.uk), Jack Burnett (jack@healthwatchlewisham.co.uk)

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1. Introduction

Healthwatch Lewisham are carrying out a research project on trans* and non-binary health experiences in Lewisham. We are doing this by interviewing people who come under these identities who live in the Borough of Lewisham or have accessed care in the Borough of Lewisham.

2. How will this research be done?

The people we interview will either be interviewed as part of a focus group, or in a one-to-one setting. The things we learn from these interviews will be analysed thematically and written into a research report.

This report will have actionable recommendations that are built from what we learnt during these interviews. These recommendations will aim to improve healthcare experiences in the borough for trans* and non-binary people.

3. What will happen if I take part in this study?

Depending on your preference and on the availability of the interviewers, you will either take part in one of the focus group interviews, or a one-to-one interview.

One-to-one interviews will be held online over video conferencing software.

In person interviews will be at the London LGBTQ+ Community Centre on London's Bankside (60-62 Hopton Street, SE1 9JH). It will take place in the quiet room, but you are also welcome to use the rest of the centre after the interview, or if you need to take some time out during the interview.

All interviews will be co-led by members of the trans* and non-binary community and will be observed by one of the researchers on the project.

Participating in this project will not influence how much support you will receive in the future from community organisations or primary care services.

4. What will happen to the information I share?

The interview will be recorded so that a typed transcript can be created and participants will be anonymised.
All information pertaining to this will be stored electronically in a password-protected folder . These files will be stored securely and encrypted.
You will be asked explicitly whether you consent to be anonymously quoted.
During the interviews you are welcome to "strike" something you say, so that it will not be included.

5. What will happen if I change my mind about participating?

You are free to withdraw from the study during or after the interview. If you do so any of the interview data collected will be erased.
You are also entitled to change your options on the consent form at any time.

6. What will happen to the results of the research?

This research will be included in Healthwatch Lewisham's project on Trans* and Non-Binary Healthcare Experiences in Lewisham, which in turn will be shared with local NHS trusts, councils, and other third-party bodies. It will also be a publicly available document.
You may request a copy of the completed report.

7. Who is funding the research?

The research is funded partially by a grant from the Care Quality Commission. Healthwatch is delivered by Your Voice In Health and Social Care, who pay the salaries of the researchers and have partially funded this project.

Please keep this copy of the information sheet and a copy of the signed consent form.