



## Healthwatch Southwark Findings from our Trans survey

September 2016

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# Background



## What is Healthwatch?

Healthwatch is an independent health and social care champion for local people. This means we represent your views to ensure services are shaped around your experiences and designed around your needs.

We are the ‘critical friend’ to people that provide, fund and monitor care. We are part of a wider network of local Healthwatch across the country, as well as a national body, Healthwatch England.



## Why we wanted to hear from the Trans community?

As a champion for patient and public voice, we want voices to count towards improving services. We know that some groups are ‘seldom heard’ and therefore we aim to engage with these communities in a targeted manner.

We want to find out about their experiences of using services and the challenges they face so that we can inform commissioners and providers about how they can improve access and experience for these people.

Healthwatch England shared with us that 8 local Healthwatches raised concerns in 2014 around access to Gender Identity Services and Gender identity Clinics. This was escalated to NHS England and the

Director of Specialised Commissioning in September 2014.

The concerns and findings included:

- Long waiting times for operations
- Lack of specialist consultants
- Lack of communication and engagement with patients
- Inequality or lack of support from healthcare professionals
- Lack of mental health support
- Lack of provision of voice therapies and hair removal

Healthwatch Southwark wanted to understand the experience of local people in the context of the national experience of Trans patients and so started a series of engagement activities.



## What we did

Initially we made contact with Southwark based charity Trans Masculine Support and Advice UK which provides online support for the Trans community. From July 2015 we started to make contact with local and national support services and charities to build relationships and seek advice on how best to engage with this community.

We created a survey with questions with multiple choice answers and space to make further comments, these were designed to be clear and easy to complete. The questions focused on what the experience was like of using health services including mental health services, the interaction with health

professionals, the ease of accessing information and asked if there were any recommendations they could make to improve the experience of Trans people accessing health services.

The survey was promoted via the Healthwatch Southwark website, e-newsletter, stakeholder forums and our supporters. We attended the Race Equality Foundation’s Health Network meeting in September 2015 where we made links with pan-London organisations that support LGBT communities which fed back on our methodology and provided links to circulate the survey.

We also attended community events and a popular Trans cabaret night in Vauxhall to promote the survey by sharing the link and handing out printed surveys for people to complete and return in self-addressed envelopes to us.

Engagement took place between September 2015 to August 2016.

## Responses received

We received 23 responses (note this is the number that filled in beyond the question about which services they have accessed) and the number of responses to each question is specified in this report.

Of the respondents, 20 were registered with a GP, 17 had used hospital services, 14 mental health services, 10 sexual health services, and 11 had been to a Gender Identity Clinic (GIC).

4 respondents had used services in Southwark. Other services used were across London including Charing Cross

GIC, Lewisham, Hackney, Newham, Islington, and Haringey, and in Surrey, Sussex, Kent, Bristol, Manchester, and Scotland.

Gender (responses = 17)	
Female, Trans woman or mtf	8
Male or mtf	3
Genderfluid	1
Agender	1
Non-binary or Trans non-binary	3 *
Agender, genderqueer, male or genderfluid	1

\* 1 further specified demiboy/ genderqueer

Ethnicity (responses = 17)	
White, White British, White Scottish, or White other	10
British, English or Anglosaxon	3
Jewish	1
Mixed	3

Age (responses = 17)	
Under 18	1
18 to 25	5
30 to 39	5
40 to 49	1
50 to 59	4
60 to 65	1

Disability (responses = 13)	
No disability	5
Disability	8 *

\* Disability included: prediabetes, Marfan syndrome, chronic fatigue syndrome, speech disfluency, visual impairment, and mental health issues including depression, OCD, and anxiety/panic disorder.

# Summary of findings

Low proportions of respondents felt comfortable talking to a health professional (24%) or agreed that healthcare professionals spoke to them with dignity and respect (27%). Many felt that this varied between professionals and depending on the topic and throughout the survey there was a strong sense of the sense of exclusion which comes with not being able to reliably trust that doctors will act respectfully and provide good information and care.

Whilst some people knew where to find general health information, information about Trans-specific issues, transition, and health after transition, was more difficult to obtain. Information on transition was often inaccurate or out of date, and guidance might not match what was happening in practice. In order to find even this information people often had to do their own research online and talk to other Trans people who had been through the process. Online, the voluntary sector and peers were more common sources of information than health professionals.

Most respondents (71%) felt that health services do not treat Trans people equally compared to cisgender people (who have a gender identity that matches the sex that they were assigned at birth or CIS). Inequalities included a sense that Trans issues are not seen as real medical issues, the fact of long waiting times for Trans medicine, being unable to trust that professionals will be respectful, not being able to seek or obtain help for other issues because of one's Trans identity, not being able to be open with

professionals, and not being addressed by the correct name or gender.

Another large majority of 70% of respondents disagreed that health services work well for the Trans community. Key issues raised were very long waiting times for appointments and treatment, lack of clarity among professionals about pathways, binary-normative services, and variable, under-resourced care. Solutions suggested included investment in services, mechanisms to improve poor services, training for medical professionals, better online information and information about waiting times, and systems to ensure the correct names and pronouns are used.

Throughout the survey, several people commented on the fact that they felt their own feelings, experiences and identity were disregarded as they tried to seek care, and attitude change is a key part of recommendations for change. In particular, some felt that being Trans is incorrectly considered to be a mental health condition itself, and that consequently they struggle to be taken seriously or cannot seek treatment for mental health problems which result from being Trans. People were vocal about this need to be taken seriously.

# What we found



## Interactions with health professionals

### Ease of making an appointment

A disappointing 36% of survey respondents found it easy to make appointments with health professionals. Two who were unsure said it was easy at the GP but not at specialist services or with mental health professionals.

It is easy for me to make an appointment to see a health professional (responses = 22)

Agree	36%
Unsure	18%
Disagree	45%

Issues with making appointments included long waits or cancellations. One person said that seeing the GP is easy but getting a specific appointment time difficult. Others found the process of getting medical appointments **“difficult and tedious”** with one referring to conflicting information about when an NHS number is needed and how to get it and one to complicated referrals - **“Seeing specialists beyond [the GP] can be difficult. Bureaucracy and wait times can lead to months or even years of being bounced between various specialists (and back to your GP) before a health need actually ends up being met.”**

Another person referred rather to the emotional difficulty of going to a

professional, **“I don't feel safe with them. They are so severely incompetent, misinformed, sadistic and underfunded.”**

### Feelings about talking to a health professional

Less than a quarter of respondents said they felt comfortable talking to a health professional, and 43% actively disagreed.

I feel comfortable talking to health professionals about my health needs (responses = 21)

Agree	24%
Unsure	33%
Disagree	43%

Some said that their comfort level depended on the professional - for example, one person did not feel comfortable talking to cis men; another said, **“I typically have to sound out a health professional to make sure I can talk to them safely.”** Another person felt comfortable around some topics but said **“some things I am uncomfortable discussing due to my relationship with those parts of my body, and due to not having much confidence [that] I'll get good information on anything vaguely Trans-specific.”**

Reasons for not feeling comfortable to talk to professionals included worries that disclosure of Trans identity would affect the quality of care, or that disclosure of mental health problems would interfere with future treatment as a Trans person.

One person described how feeling misunderstood and overridden by others had made it impossible to talk to doctors any more - *“I don't feel as if doctors understand my feelings. There is too much of a focus on medication as a solution based on my previous history, and so I don't talk to them. I want to talk about hormones, I want to understand things, but I can't talk to these people... So I don't go. I don't talk.”*

Another person said that the environment did not feel honest, relaxing or open.

### Being treated with dignity and respect

Again, only around a quarter of respondents agreed that healthcare professionals spoke to them with dignity and respect, with slightly smaller numbers disagreeing.

#### Healthcare professionals speak to me with dignity and respect (responses = 22)

Agree	27%
Unsure	50%
Disagree	23%

Again, many people's experiences varied between health professionals. One respondent with mixed experiences said, *“Some people are of course kind and, more importantly, they do their jobs. Others on the other hand are frankly rude and dismissive”* - being frequently mis-gendered was an example of this. Another commented that being listened to was important and that *“when I've had bad experiences it's never been someone with bad intentions, they just didn't realise how inappropriate they were being.”*

One respondent said that while health professionals are not actively rude - *“there is no warmth to their communication...It is like they feel embarrassed, and they don't know where to look. I often feel that were something said to me by a third party, the health professionals wouldn't defend me, so they are not my advocate. I often feel like a burden, taking up time and space for 'real' people, with 'real' problems.”*

Another clarified that while most professionals were respectful in interactions the approach taken was not - *“being referred to the mental health service rather than a gender clinic was something I found to be disrespectful.”*

A person with negative experiences said, *“They speak to you - when they find the time after years of waiting - in an offensive and belittling manner.”*

## Interactions with health professionals

### Finding health information

A slight majority of respondents said they knew where to find information on staying healthy. Two people implied that they know where to find information about general health but not for Trans-specific issues.

#### I know where to find information about keeping healthy and well (responses = 20)

Agree	55%
Unsure	40%
Disagree	5%

*“Where? We are ignored by doctors, ignored by gender identity clinics...”*

*“I do, but only because of its importance to me, not because it's always easy to find.”*

One person noted importantly that information is focused around the point of medical transition, and not about related issues afterwards - for example, pains as a result of chest binding or sexual issues, *“Where do you get info on that? Or find someone who knows if I even should be concerned by it?”* They said that the information they can find *“is more like collecting a bunch of opinions/experiences and assuming what's probably true.”*

### Preferred information sources

The most common source of information for respondents was online (85% of respondents), followed by the voluntary sector (65%) and friends and family (60%), with only 55% of people telling us they get information from health professionals - one said, *“I reject health professionals' advice because I feel that they reject me.”*

Other sources of information mentioned were:

- Clinical guidance and best practice/evidence summaries.
- Young Trans girls aged 14+ (who are often sex-workers to buy their hormones illegally), who are a good source of information about hormones and where to get them.

### Clarity of information about gender transition

Only 5% of respondents (one person) felt that information about transition was clear, with a strong majority of 75% disagreeing.

#### Information around transitioning is clear and straightforward (responses = 20)

Agree	5%
Unsure	20%
Disagree	75%

One person commented in particular that *“it is not clear or straightforward for people who identify outside of the binary.”* Another noted that *“wait times etc. are rather hidden.”*

Themes included:

- Information being *“convoluted, outdated and sometimes contradictory”*, with health professionals often working from old information or not following the *“vague ‘best practice guidelines’”* which are available.
- People having to do their own research online and outside the NHS, though this could be problematic as information might not be local.
- The necessity of talking to other Trans people to find useful information - *“It's completely impossible to find out anything without consulting those already going through the processes to transition.”*



### Overall experiences of health services

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### Equality of treatment by health services

Only 10% of respondents felt that health services treat Trans and non-Trans people equally, and 71% disagreed.

I feel that health services treat everyone equally; it does not matter if you are Trans or not (responses = 21)	
Agree	10%
Unsure	19%
Disagree	71%

*“By and large, I feel that Trans people are seen by the medical profession as being ‘difficult’ patients with idiosyncrasies that unfairly drag politics into medicine. Most health professionals see it as some kind of lifestyle choice which either complicates their job or is irrelevant and not deserving of their consideration.”*

*“I believe 7 year average wait times for certain treatment, as well as general condescending reception by doctors and staff, is not common in non-Trans medicine.”*

*“Seeing health care professionals I’ve never seen before makes me nervous; I can’t trust I will be treated with any respect at all. Whilst it’s still hit or miss that I’ll be respected, services will never be equally accessible for me.”*

People felt that their Trans identity meant they could not seek or obtain help with other issues - *“Every issue, you hear, is due to taking hormones (wrong)’; ‘[I] feel I can’t speak about mental issues (which are due to being Trans), because they may withhold future treatment (common).”*

Another person said that as a genderfluid/intersex person they are unable to be open with professionals, because they might not receive the correct healthcare and would not have easy access to healthcare without having to explain. *“Even at UCH I am only ‘out’ to a couple of healthcare professionals and definitely not all.”*

As another example of inequality some people mentioned being mis-gendered or professionals not using their preferred/ correct name - *“despite giving my GP my deedpol, they refused to change my name on their records.”* *“Reading out the wrong name in the waiting room is always awkward.”*

#### Overall opinion of health services

No-one felt that overall, health services work well for the Trans community. One of the three who said they were ‘not sure’ added that while it had worked for them personally, *“I understand this isn’t the case for everyone...”*

Overall, I think that health services work well for the needs of the Trans community (responses = 20)	
Agree	0%
Unsure	30%
Disagree	70%

*“Overall, I think health services are pretty abysmal for Trans people.”*

*“Outside of gender-related services, health professionals have little to no awareness of Trans people and their needs, and most Trans people I know would not generally assume [they will] be well treated by them.”*

***“The rates of suicide of Trans people who aren't able to transition are so high.”***

Extremely long waiting times were a common problem cited. One person described waiting over a year for their first Gender Identity Clinic (GIC) appointment, which was then delayed a further six months and which did not involve a blood test or hormone prescription despite psychiatric recommendation.

During this period the person was self-medicating with ‘unsafe’ hormones, and had ‘disintegrating mental health’ and suicide attempts. The second appointment is scheduled for three years after the initial referral.

Another person said that having moved house they would have to wait two years to be seen in a new GIC, even for a minor issue, and that the nearest clinic was two hours away by train. Another person said their appointment had been cancelled twice meaning a seven-month delay. Others described waiting lists as ‘colossal’, ‘abhorrent’ and ‘appalling’ - ***“The health services are totally overwhelmed with the amount of Trans people.”***

As well as waiting times, barriers to accessing services included gatekeeping by GPs ***“who typically are woefully uninformed about the system itself and the general needs of Trans people.”*** Some GPs are unaware that young patients do not need to be referred to the GIC via Child and Adolescent Mental Health Services (CAMHS).

Throughout the survey, several people commented on the fact that they felt their own feelings, experiences and identity were disregarded as they tried to seek care:

***“The fact we have to prove our gender to two different cis professionals is ridiculous.”***

***“You have to jump through hoops and prove yourself worthy. And even then your opinion over your own feelings counts for little.”***

***“I live as a woman, I self-medicate, I am taken to be a woman by everyone... how much more do I need to prove myself?!”***

***“Even if I come to a decision that is right for me, it then has to be verified by another authority figure? How is this different from any other way in which I feel my body has become the property of other people? How is this giving me the chance to make my own decisions?”***

Two people noted that services can be binary-normative and this makes getting help even more difficult for some -

***“Health services often refuse to help non-binary individuals and those who do not conform to what cis people’s assumptions of what transgender is.”***

One of these respondents thought this situation might be improving. Once seen by the GIC, two people said they found care to be variable and under-resourced -

***“there seems to be somewhat of a lottery regarding whether or not you get a specialist who follows the current guidelines and treats you well.”***

# Recommendations

We asked respondents for their recommendations on what would make it easier for Trans people to use health services. 13 people shared their views.

Four respondents followed on from the issue of **waiting times and access**, and quality of services, by arguing more investment is needed. Services should *“invest more in keeping to the 18-week rules.”*

*“Fund services: quicker (much quicker) appointments, and only rare cancellations! Make the path to transition quicker!! Take us seriously, fund us! Don't force children into sex work to buy black market hormones.”*

*“Poor people [should be able to] access Trans care of as good quality as [that accessed by] rich people... The best care I have had is when I pay myself, even though by doing this, I know I am jeopardising completing my Trans healthcare.”*

One person who had written about the risks of ‘taking dodgy hormones from the black market’ said that doctors need to *“take self-medicating seriously - prescribe and monitor.”*

As well as investment, suggestions for improving service quality included *“clearer grievance procedures and complaints departments that take Trans needs seriously, and have the ability to implement improvements rather than simply issue apologies.”*

One person suggested allowing greater **patient choice** of provider, *“so the useless ones can trim down to bones and the effective ones prosper.”*

Six respondents said there was a need for better, compulsory **training for health professionals** around Trans and intersex issues. This included administrative staff as well as GPs. Training should include Trans people’s identities (including non-binary identities), needs, experiences and rights; one person also mentioned sexual health. GPs needed better information on the role of a GIC, waiting list lengths, and how to make a referral, and gender identity specialists may also need more up-to-date training. One person described the emotional impact of exclusion which professionals need to be prepared to deal with,

*“If we do identify as Trans be prepared for the blowback that might occur when you treat us... When you are mocked, physical attacked, disenfranchised, marginalized, and ignored by society, it can be painful to experience acceptance and compassion. Often we lash out or shut down at our care givers. We don't mean to, but we do. Trust is a hard thing to earn for many Transgender people.”*

As part of training, attitudes need to be addressed - *“Encourage staff to work under the informed consent model instead of pathologizing us.”* Attitudes and respect were seen as an issue of

overarching importance: two people said that being Transgender should not be treated as a mental health issue; two that they just wanted to make their own choices about their bodies and not have to *“jump through holes to get access to medical transition.”* Services should also *“make non binary transition the same priority as binary transition.”*

Using the correct gender, names and pronouns was seen as important, through **updating records and records systems** and in personal interactions - *“If there is a doubt over our perceived gender bite the bullet and ask us what we’d like to be called.”*

*“See us as real people.”*

Improved **information** is also needed. *“There is no one-size-fits-all approach as the Trans spectrum is vast and hugely challenging. Clearer information available on-line would be of enormous benefit, especially surrounding an individual’s suitability for transition and overall quality of life.”* In particular, services should confirm receipt of GPs’ referrals and advise what waiting time to expect.