Non-binary Experiences of Healthcare

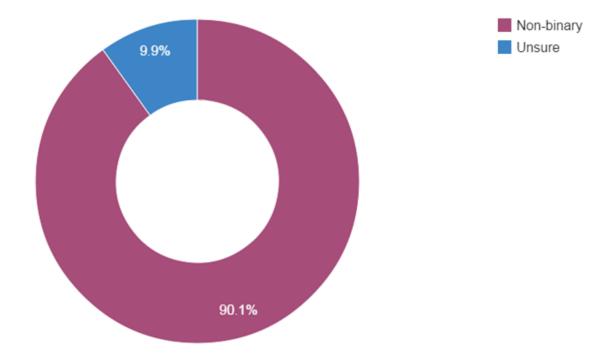
Research by Action for Trans* Health

121 people took part

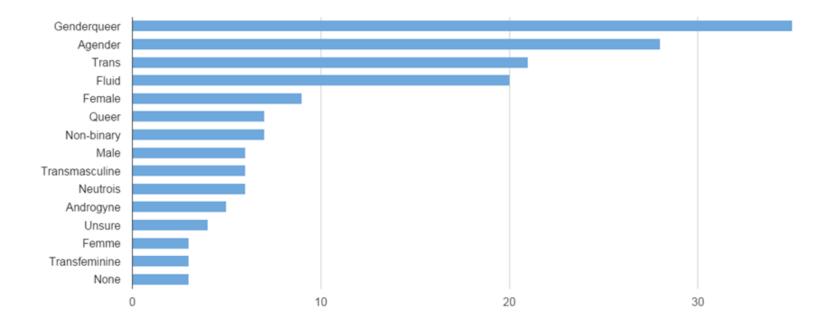
7 additional results were excluded, as the participants said they were binary identified.

There may appear to be numerical discrepancies, as many participants did not answer every question.

Gender identity of participants



Specific identities of participants



40

Many people named more than one gender identity

Sample answers:

"Butch, masculine of centre, hearing the word 'she' as a descriptor doesn't feel appropriate, and being a 'woman' doesn't feel right either. But I'm not male."

"Gender Fluid, including Agender"

"I stopped trying to describe it years ago, the unsure is not something that causes me concern"

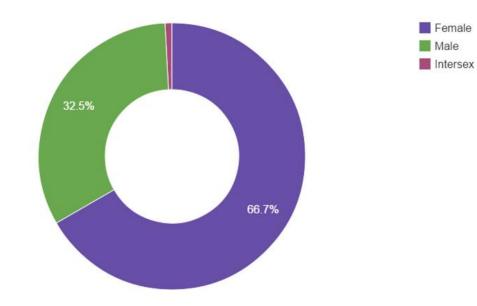
"Fluid and occasionally absent, but "non-binary transguy" works as a label"

"Partly male, partly no gender"

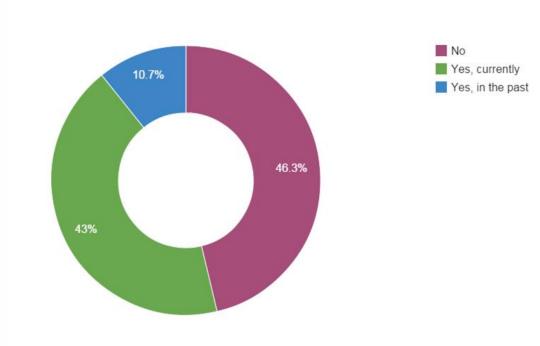
Identities named by fewer than 3 participants:

| Woman | Mixed |
|-----------------|------------|
| Transwoman | Irrelevant |
| Demi-girl | Intersex |
| Demi-boy | Genderflux |
| Bigender | Demi-guy |
| Varied | Butch |
| Unclear | Absent |
| Trigender | |
| Polygenderfluid | |
| Other | |
| | |

Sex that participants were assigned at birth



More than half of participants have tried to access transition related healthcare from a health service provider



Concerns around seeking treatment

| Fear of treatment being denied | | | |
|---|-----|----|--|
| Unsure if treatment is destred | | | |
| Fear of societal reactions | | | |
| Barriers due to disability | | | |
| Lack of knowledge on how to access treatm | ent | | |
| Limited understading of risks | | | |
| Fear of friends/family reactions | | | |
| Concern that others need services more | | | |
| Fear of regret | | | |
| Treatment desired is not medically possible | 20 | 30 | |

Being denied treatment was the primary concern

Sample answers:

"have been scared to seek treatment as a non-binary person due to prejudice, potential mistreatment/abuse, and potential of being refused treatment"

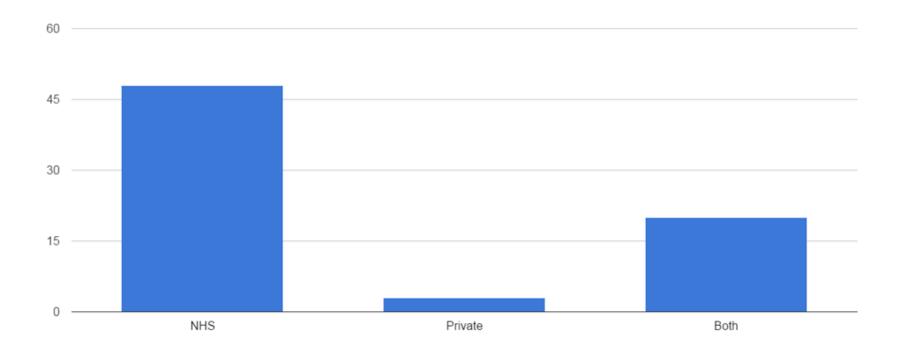
"I don't want to have to pretend to be someone I'm not (again) so I can get the treatment I need."

"That I would be seen as 'not trans enough' because I don't fit a certain standard of what it means to be transgender in their eyes."

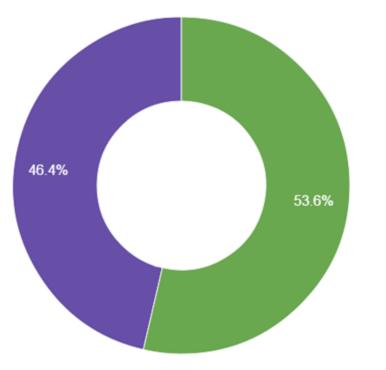
"Perception we're not allowed to unless we're binary Trans and stories of biological essentialism in GIC's."

"I'm worried I won't be taken seriously unless I pretend to be binary trans"

Service used when seeking treatment

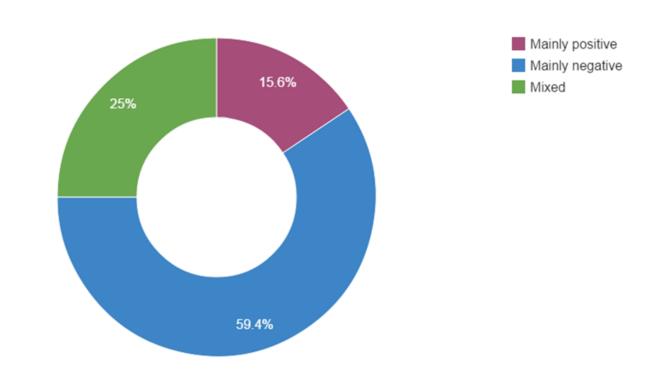


Of those who tried to access NHS treatment, proportion who were 'out' about being non-binary



Out Presenting as binary

Experiences of the NHS while 'out' as non-binary



Experiences of the NHS while 'out' as non-binary

"The GPs I have had have been brilliant, but the GIC were the worst and made me feel like I was a child going through a phase and I felt like I wouldn't be able to access the top surgery I was after until I decided to transition "properly" and take testosterone (which I did not want)"

"Favourable - NHS practitioners at CHX have been helpful"

"Initially I was told that I would not be endorsed for any treatment unless I presented as a binary-identified person and followed a prescribed (binary) treatment "pathway". I was referred by the GIC for cognitive behavioural therapy and blocked from seeing GIC clinicians during this time."

"Total lack of interest resulting in being told I cannot be helped and to not come back, where I now consider I no longer have a GP"

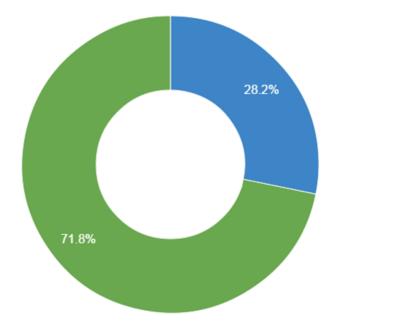
"I was treated well by my GP, but the gatekeeper for a referral was dismissive and insistent I "choose" within the binary. She eventually agreed to send my referral, but advised me that she would be advising against it being accepted due to my non-binariness."

"I wasn't specifically asked to describe my gender identity, as in, put a single label to it. We talked through what kind of treatment I was looking for and that seemed far more important than any label."

"I wanted to access HRT from an NHS GIC and discuss the possibility of having some form of surgery but wasn't able to access what I wanted because of my non-binary identity. I am now considering going to see a private GIC as I feel the outcome may be better than my experience with the NHS GIC."

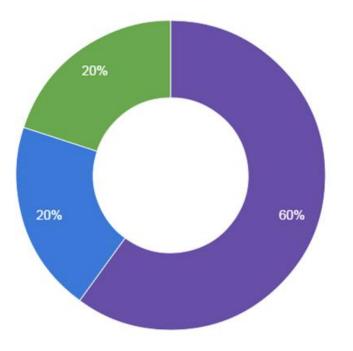
"At [my] GIC, when I said that GRS was not my main goal. I Was told by the Therapist "We do not support shemales"! Then psychologist threatened to stop my get coz I was over 50 years old."

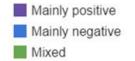
Of those who tried to access private treatment, proportion who were 'out' about being non-binary



Out Presenting as binary

Experiences of private services while 'out' as non-binary





Experiences of private services while 'out' as non-binary

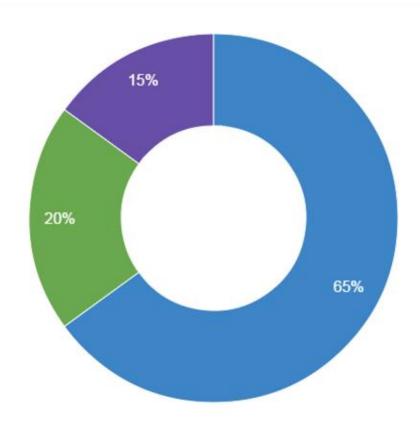
"Within 3 weeks of accessing private treatment I had my first appointment. I felt listened to, understood, and respected. Within a few hours I had a referral for top surgery, and within 4 months I was able to have it done."

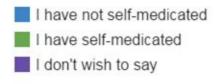
"It was a good experience. Expensive, but worth it to get to start hormones and the next step in my transition to being happier mentally."

"I have enquired about top surgery without hormone treatment and have been told that I would need a GP or GIC referral (unlikely as a nonbinary trans person) or would not be able to have the treatment at all."

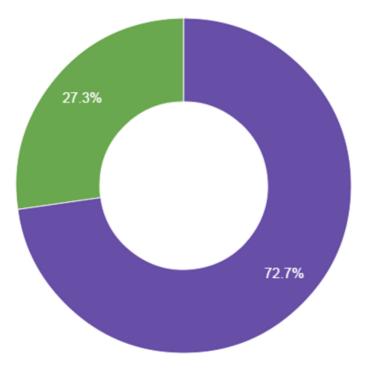
"I chose to go to Gendercare for my private treatment and I couldn't be happier with my choice. The fact I was non-binary was never a problem as they see many other non-binary patients. I was on testosterone within a couple of months and my diagnosis showed no problems with me being NB. Gendercare also has a policy where you can dress how you want at your appointments without fear of them judging you or it affecting your diagnosis/treatment. If I went NHS I would have felt I would have had to "man it up" (in clothing and mannerisms) in order to access treatment."

Self-medication





Experiences of self-medication



Positive experience Mixed experience

Reasons for self-medication

| Long waiting lists | | |
|---|------|-----|
| | | |
| | | |
| Lack of trust in healthcare professiona | S | |
| | | |
| Have been denied treatment | | |
| | | |
| | | |
| Want to 'try' hormones without commit | ment | |
| 2.5 | 5 | 7.5 |

Experiences of self-medication

"I trust myself far more than I trust healthcare professionals. Mostly positive experience though with underlying anxiety about unreliable supply issues (due to prescription restrictions)"

"I was aware that the NHS would take months or years to prescribe anything."

"The Estradiol was successful. The use of an Anti-Androgen is dangerous without prescription & monitoring I experienced low sodium levels because of these."

"Disclosing self-medding to the Gender Dysphoria Service was met with indifferent "a lot of people we see are doing that". I've had one full blood test, which the GP surgery only did when I pointed out the recommendation on the GDS letter."

"I did it because I wanted to feel more comfortable and knew I would struggle to get it through the NHS. I also feel that I should not need permission from a doctor to take testosterone although I understand the necessity of having an endocrinologist's opinion."

"I was frustrated with the long wait (3 years) for hormones and extremely dysphoric so a friend gave me some of his testosterone gel."

"I distrust the medical gatekeepers so I decided to take my healthcare into my own hands. I stopped self-medicating a few months after I started because my GP refused to monitor my condition."

Ideas of campaigns to improve access to healthcare for non-binary people

| Training healthcare professionals | | |
|-----------------------------------|-------|----|
| Educating the general public | | |
| Change NHS beaurograpy | | |
| Removal of gatekeepers | | |
| Shorter waiting lists | | |
| Gathering anonymous feedback | | |
| 12.5 | 25 37 | .5 |

Ideas of campaigns to improve access to healthcare for non-binary people

Suggestions made by only one participant:

Anti-racism Anti-ageism Awareness of intersex Welsh access to more GICs Legal recognition of non-binary genders Pro-choice Breast cancer awareness Awareness of pathways List of non-binary friendly surgeons

Sample answers:

"Training so that you can expect all NHS staff (at the very least) to be ready for non-binary people."

"GICs run by trans people for trans people."

"The NHS should respect the wishes of non-binary people and put gender markers other than male or female on records and forms...but these should only be made visible to a given doctor/viewer of medical records with the consent of the individual." "Mandatory training for gender clinic staff on non-binary identities and needs."

"Getting information into schools through talks, or leaflets, letting non binary teens know they can go somewhere for their health." "I would argue that training healthcare professionals in trans health issues, both related and unrelated to "transitioning", would be the best way forward."

Conclusions

Participants have a wide range of specific identities, with many naming more than one.

Two thirds of participants were assigned female at birth.

More than half of participants had tried to access transition related healthcare.

The primary concern around seeking treatment was fear of treatment being denied.

The fear of being denied treatment due to being non-binary is pervasive.

Most participants had used NHS rather than private services.

46% of those who tried to access NHS treatment presented as binary, as did 72% of those who tried to access private treatment:

A huge proportion of non-binary people are presenting as binary to try and access treatment.

84% of those who were 'out' as non-binary and sought NHS treatment had negative or mixed experiences. Only 40% of those who were 'out' as non-binary and sought private treatment had negative or mixed experiences.

Conclusions

The experiences of those who were 'out' and tried to access NHS treatment were shockingly poor.

Experiences were generally better in private services.

20% of participants report self-medicating, the figure is probably higher as 15% chose not to say.

Experiences of self-medication were overwhelmingly positive.

Most people chose to self-mediate because of long waiting lists and a lack of trust in healthcare professionals.

By far the most popular campaign suggestion was training healthcare professionals.

Educating the general public and changing NHS bureaucracy were also considered important.

Any questions?

Get in touch with us: info@actionfortranshealth.org.uk