



# Falling through the cracks

Non-binary people's experiences  
of transition related healthcare

*Action  
for  
Trans\*  
Health*

**Cover:** A picture of a young Stormé Delarverie (1920-2014). Stormé was a mixed race 'stone butch-dyke' and drag king. Stormé was the first person to throw a punch at the Stonewall riots, an uprising of queer and trans people against police repression and one of the key moments in the history of the LGBT movement. Stormé incited others to take up action by shouting "Why don't you guys do something?"

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## 1 Introduction: Non-binary people falling through the cracks

Non-binary people make up an increasingly significant proportion of the trans population. There has been a huge increase in the number of non-binary people who are, and want to be out – whether that be in the workplace, at school, college or university, or with their GP<sup>1</sup>. In the past few years, we have seen traditionally binary trans groups and organisations explicitly opening their doors to non-binary people<sup>2</sup> and are beginning to see non-binary representation within larger LGBT organisations, with non-binary people being consulted by organisations such as Stonewall and LGBT Foundation. Yet despite these not insignificant gains, non-binary people have a long way to go before they reach parity with even binary trans people in terms of healthcare.

We also know that living with gender dysphoria and the stresses of living in a transphobic society can have a significant impact on trans people's mental health<sup>3</sup>. According to the 2012 Trans Mental Health Study, 35% of trans people attempt suicide at least once, with 25% of trans people attempting again<sup>4</sup>. We know that suicide attempts are more likely before transition (63%), and during transition (7%), than after transition (3%)<sup>5</sup>. To compare, various self-report studies place the proportion of the general population who have made a suicide attempt between 1-4%<sup>6</sup>. We also know that access to transition related healthcare has a significant positive effect on trans people's mental health. Whilst the Trans Mental Health Study does not discuss mental health by the gender of participants, 35% of their participants defined their gender outside of the binary.

Due to lack of comprehensive gender identity or trans status monitoring within the NHS and other healthcare providers, it is impossible to get large bodies of data about trans people's experiences of medical care, let alone non-binary people, as they are a minority within a minority. In this report, we utilise the experiences of our members and service users, and our expertise in working with them, to draw out common themes and issues that those outside of trans communities may be less familiar with. **We hope that the NHS and other organisations will help us to combat this lack of evidence by implementing gender identity monitoring**

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<sup>1</sup> See the rise of campaigning groups such as the Non-binary Inclusion Project, support groups such as Non-binary South West, and creative projects such as Beyond the Binary Magazine.

<sup>2</sup> Sparkle, Transforum, Morf Binder Scheme to name a few.

<sup>3</sup> Hendricks, M. L., & Testa, R. J. (2012). A conceptual framework for clinical work with transgender and gender nonconforming clients: An adaptation of the Minority Stress Model. *Professional Psychology: Research and Practice*, 43(5), 460.

<sup>4</sup> [http://www.scottishtrans.org/wp-content/uploads/2013/03/trans\\_mh\\_study.pdf](http://www.scottishtrans.org/wp-content/uploads/2013/03/trans_mh_study.pdf)

<sup>5</sup> 2012 Trans Mental Health Study available: [http://www.scottishtrans.org/wp-content/uploads/2013/03/trans\\_mh\\_study.pdf](http://www.scottishtrans.org/wp-content/uploads/2013/03/trans_mh_study.pdf)

<sup>6</sup> Hawton and van Heeringen (2000) *The International Handbook of Suicide and Attempted Suicide*

**across services so that health inequalities specific to trans people can begin to be better understood** through more robust data collection.

Non-binary people seeking medical and surgical interventions through Gender Identity Clinics, whether NHS or private, is nothing new. What is new is an emerging culture of trans people who are frustrated by having to hoop-jump and bend their stories in order to fit established medical narratives of trans-ness, when these people have their own valid narratives and experiences. Non-binary people tell us repeatedly that **they would like to be able to be honest and open about their identities with their healthcare professionals.**

The following report is based on the experiences of 114 non-binary people who have tried, with various degrees of success, to access transition related healthcare both privately and through the NHS. These findings reflect themes often discussed by non-binary people in self-generated media such as vlogs and blogs and within support groups, including **self-medication**, fear of **treatment being refused**, people feeling that they must **present as binary in order to get appropriate treatment**, being out as non-binary leading to **negative experiences of healthcare services**, and **long waiting lists**. We will return to these themes in the recommendations section of the report.

## 1.1 About Action for Trans Health

Action for Trans Health is a UK network of trans activists and organisations campaigning for trans healthcare rights. Our network of individual members and affiliate groups makes us the largest UK campaign for trans healthcare. We welcome non-binary individuals and organisations as members and affiliate members.

Action for Trans Health have three main aims:

- Raising funds to give small cash grants which facilitate trans individuals' access to healthcare.
- Engaging with medical professionals about trans health
- Engaging the trans community about health issues; by providing sexual health workshops, harm reduction information on self-medicating, information on NHS funding structures, etc.

Action for Trans Health believes in a world where healthcare is truly democratic, where trans people have full bodily autonomy and where trans people can be open with healthcare professionals and make informed choices about their own healthcare needs, bodies and lives. **You can become a member or donate to Action for Trans Health via our website [www.actionfortranshealth.org.uk](http://www.actionfortranshealth.org.uk)**

Facebook: [facebook.com/actionfortranshealth](https://facebook.com/actionfortranshealth)    Twitter: @act4transhealth

## 1.2 Methodology

Data was collected through an online survey of 114 non-binary identified individuals who were recruited through personal contacts and through social media. Follow up skype interviews were conducted with people from under-represented groups and who had particular experiences we wanted to examine in more depth: non-binary people undergoing self-medication, non-binary people of colour, non-binary disabled people, non-binary people who identify as intersex, and non-binary people who experience transmisogyny<sup>7</sup>. It should be noted that our sample size, whilst as far as we know is the largest set of non-binary people sampled so far for a healthcare study, is still quite small. As such, we consider the results to be indicative but not statistically representational.

## 2 Identity

Many of those who participated listed more than one identity. These included some terms relatively well known by healthcare professionals, such as trans woman and trans man, and others with which they are less familiar, such as demi-boy, demi-girl, intersex, polygenderfluid and irrelevant. Definitions of these terms can be found in section 10. Participants were given the opportunity to explain their gender identities in more detail and many did. Sample answers include;

*“Fluid and occasionally absent, but “non-binary transguy” works as a label”;*

*“Gender Fluid, including Agender”;*

*“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”;*

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

66.7% of participants were assigned female at birth. This means that this report may overlook some significant issues for non-binary people assigned male at birth, as they were less well represented in our sample, with only 32.5% identifying themselves in that way. A very small proportion, 0.8% of our sample, identified their birth assignment as intersex.

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<sup>7</sup> Transmisogyny is a specific form of oppression defined as the confluence of transphobia and misogyny which affects trans women and some non-binary people who were assigned male or intersex at birth.

### 3 Diagnostic criteria and “Real Life Experience”

#### 3.1 Identity and Diagnosis

We note that many clinicians working in gender identity clinics seek to build a sense of their patient’s identity over the period of time that they are working with them. In this way, they seek to establish whether the patient’s identity is consistent over time, as both a diagnostic tool and a way of determining which treatments may be appropriate. A significant theme emerging from our study was a sense that clinicians, in particular NHS clinicians, were more concerned about how non-binary patients identify over what treatment(s) they require. As one respondent said:

*“[The clinician] couldn’t seem to get their head around my bigender identity. Appointments focused way too much on asking questions about what bigender means and not enough on what I actually wanted”*

Where respondents had identified good practice, this is because consultations focused on treatments rather than identities. As one participant described:

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

A focus on the consistency of a patient’s gender identity as a diagnostic criterion and as a way of determining appropriate treatments has a significant negative effect on non-binary patients, especially those who experience fluid and shifting identities. Treatment provided by gender identity clinics are used to treat gender dysphoria, whether a patient’s identity is fluid should be irrelevant to the question of whether they consistently experience gender dysphoria. The fear of being denied or delayed treatment on the grounds of non-binary / fluid gender identities was a significant concern for the majority of respondents, and a small but significant number of respondents said that they had been denied care on this basis. **We believe that the patient consistently identifying a particular treatment as desirable and/or necessary is a more appropriate tool for diagnostic evaluation than the words the patient uses to describe their identity.**

Whilst this may have some negative impact on those who access gender identity clinics not knowing what treatments are available, we are aware that many trans people access this information through other means, such as online and in person through support groups and networks. Often patients are expected to carry out their own research into their healthcare. As one participant said:

*“When at appointments I often feel like I am being tested as to whether I have done the research or not. As if the access to treatment is based upon whether or not I have been a good queer and done my homework. Surely if the gender*

*identity people are going to set themselves up as experts in trans health it should be them providing the information to me?"*

We believe that access to treatment should not be contingent on the patient having the time and resources to access information on treatment options. **Gender identity clinics should endeavour to ensure that clear and accessible information regarding treatment options are made available to service users.**

### **3.2 Real Life Experience**

Another key diagnostic factor is Real Life Experience (RLE). RLE refers to a period of one to two years whereby the trans patient must live in "their preferred gender role" before access to some forms of gender affirming treatments become available. RLE is essentially used as a diagnostic criterion, whereby if a patient shows commitment to living in their "preferred gender role" for a long period of time, they are seen as showing the consistency of identity which is used for diagnosis and treatment evaluation. Proof of having undertaken RLE is often provided via employment / education records or a deed-poll.

Many of our non-binary service users feel that Real Life Experience discriminates against non-binary patients, as there is no unitary understanding of what a "non-binary gender role" looks like. Non-binary people have heterogeneous identities, and may wear a wide range of clothes, adopt gendered or gender neutral pronouns, or use gendered or gender-neutral names. In practice, RLE forces many non-binary patients to adopt clothes, pronouns, and names which their clinicians read as being associated with the opposite binary gender to which they were assigned at birth in order to meet criteria designed for binary trans people. As one participant said:

*"I am an intersex person with a non-binary gender identity. [Clinicians] refused to believe that I had undergone RLE because despite changing my pronouns from she to they, I had not changed my name. I don't see why my name has to change just because [Clinician] thinks it's a 'female name'. I'm intersex and non-binary, I have never been female."*

Not only does RLE discriminate against non-binary people for whom there is no shared understanding of what a "non-binary gender role" is, the assumption that patients have a binary sex and its conflation with gender within RLE is a significant barrier for intersex and non-binary people who seek treatment.

Moreover, some non-binary people face problems providing evidence of their RLE if they are not employed or in education. As one participant said:

*"I had a lot of trouble proving that I had undergone social transition, because I had no boss or teacher who could vouch for me. There was no-one official*



*enough to prove that I was “official” enough... I had to get someone from the job centre to do it for me, but it took ages. I think it delayed my transition by at least a year”.*

26% of trans people are unemployed<sup>8</sup>. We do not have any data on the proportion of non-binary people who are unemployed, but it is likely to be higher for those who not ‘pass’ as a binary gender due to most workplaces not meeting non-binary people’s needs, for example, by having gendered uniforms or dress codes. Additionally, 51% of trans students consider dropping out of further and higher education, the two main reasons cited for this is discrimination on campus, and health problems<sup>9</sup>. Again, this is likely to be higher for trans people who do not ‘pass’ as a binary gender. Whilst proof of RLE is not required to be from an employer or institution of education, it is often difficult for trans people to provide evidence of RLE when they are not employed or in education. This can be especially frustrating for non-binary people, as they are more likely to be unemployed and not in education, and may not wish to undergo a change of name and so cannot use a deed-poll as proof of RLE.

We believe that RLE is problematic and needs to be dropped as part of diagnostic evaluation. However, if it is to be a part of diagnostic evaluation at all, should be made more flexible to account for non-binary people’s needs. RLE should be less about fitting an imaginary cross-binary gender role, and more about “exploring gender”. If ‘proof’ needs to exist, it could be proved by when the patient first approaches a trans support group, joins a forum online, or gets in touch with their GP. Perhaps a more significant measure, however, would be **ensuring that the service user has good support systems in place and feels empowered to choose to be out in situations where they would like to be and it where it would be beneficial to them**, for example, with their GP, within community support spaces and within their workplace’s LGBT network.

#### 4 Treatment

53.7% of non-binary respondents have tried to access or are currently trying to access transition related healthcare from a healthcare provider, with 46.7% having never tried to access transition related healthcare yet. When thinking about their concerns around treatment, non-binary people list barriers due to disability, lack of knowledge on how to access treatment, and fear of societal reactions as significant concerns. 35% listed fear of treatment being denied as their primary concern regarding transition related treatment. Sample answers included;

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<sup>8</sup> A 2010 [Count Me In](#) study found 26% of trans people are unemployed and a further 60% earn less than £10,000 a year

<sup>9</sup> 2014, NUS, *Education Beyond the Straight and Narrow* <http://www.nus.org.uk/Global/lgbt-research.pdf>

*“I 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”*

**Participants fear of being denied treatment due to their non-binary identity is perhaps the most striking theme within the dataset, with all of the participants from the follow-up interviews discussing this fear in depth.** This concern led to a significant number of participants presenting as binary in order to receive treatment. This concern was higher for people who were undergoing private treatment, with 71.8% of respondents presenting as binary in order to access treatment, compared with 46.4% presenting as binary within NHS gender identity clinics. We interpret this to mean that patients are more likely to be concerned about denial of treatment when they have more to lose financially. Additionally, a number of service users report that they have accessed healthcare privately after being denied NHS treatment; this could explain some patient's reluctance to be out within the private setting.

We believe that all healthcare should be free and accessible to all, regardless of how a person identifies. We also believe there is urgent need for **gender identity healthcare providers to implement significant culture changes in order to build trust with non-binary patients so they feel comfortable being 'out' within a clinical setting.** This is especially important when considering the non-binary patients who may not wish to follow the traditional binary model of transition, as in these cases their non-binary identity could be considered clinically relevant information.

Less than 2% of participants listed fear of regret as a significant concern, which concurs with the Trans Mental Health Study's findings that very few trans people regret the physical changes undergone as part of transition<sup>10</sup>. There is a widespread perception amongst non-binary people that clinician's responses to non-binary patients are informed by a belief that non-binary people are more likely to regret their treatment, especially if their gender identity is fluid or multiple<sup>11</sup>. Certainly, the fact

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<sup>10</sup> Trans Mental Health Study 2012, available online: [http://www.scottishtrans.org/wp-content/uploads/2013/03/trans\\_mh\\_study.pdf](http://www.scottishtrans.org/wp-content/uploads/2013/03/trans_mh_study.pdf)

<sup>11</sup> As one participant said *“I got the impression that they didn't trust what I was saying, like I was going to suddenly turn around after I had my top surgery and say 'hang on guys, I want*

that consistency of identity is often used as a diagnostic criteria instead of consistently requesting a particular treatment shows that clinicians seem to see trans people with binary genders as more 'stable' and at less risk of regretting their transition. Our findings here offer a significant challenge to this narrative.

Further, whilst there are cases whereby trans people (including non-binary people) genuinely regret their transitions, the number of these cases is very small and disproportionately reported on within the press. We believe that **the narrative of transition regret is overly binary focused and excludes non-binary peoples experiences**. As one interviewee said:

*"I am a non-binary transmasculine person... in order to get my top surgery, I had to undergo HRT that I didn't really want or need in order to fit what they think a transition should look like. My dysphoria was only really about my chest and now I have had surgery I have stopped taking testosterone. I worry whether people see this as a detransition. It's not".*

Because trans healthcare often assumes a binary transition, some non-binary people feel that they are forced into a particular pathway of treatment which they do not want. This is particularly the case for non-binary people who want top surgery but do not want HRT, as HRT is often a prerequisite for top surgery. Several of our service users report that when they have been open about wanting top surgery but not HRT, they have been denied treatment altogether. As such, for those individuals, undertaking an unwanted HRT treatment is necessary to access their desired treatment of top surgery. After they have received top surgery, like the above participant, their choosing to no longer undergo HRT is often seen within a framework of transition regret. We prefer to see these actions as "re-transitions" rather than "de-transitions" as they do not involve a return to the gender assigned at birth.

However, the phenomena of non-binary people re-transitioning does raise significant concerns over the appropriateness of the current binary-focused protocol for treating non-binary people. **A more flexible approach to treatment options is required in order to fit non-binary patients who fall outside of the traditional binary treatment model.**

## **5 NHS or Private Healthcare?**

Many of our respondents, approximately 17%, had engaged with a combination of both NHS and private healthcare services in the course of their transition. This is quite common across all trans people, due to the current strain on NHS Gender

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*these babies put back on!" They think that you are going to regret your transition just cause on some days you feel more femme and others more butch".*

Identity Services resulting in very long waiting lists and delayed treatment<sup>12</sup>, which drives patients towards private healthcare options.

Less than 1% of our sample used exclusively private services, whilst the majority, approximately 40% of our sample, exclusively used NHS services. We know that trans people suffer disproportionately from unemployment and employment discrimination<sup>13</sup>, and that many trans people become estranged from their families upon coming out<sup>14</sup>. With non-binary people being offered very little in the way of legal rights or recognition, including within specific trans pieces of legislation such as the Gender Recognition Act 2004, it is easy to see why private healthcare is simply not an option for the vast majority of non-binary people.

71.8% of respondents presented as binary in order to access treatment from private clinics, compared with 46.4% presenting as binary within NHS gender identity clinics. Of those who were out as non-binary within the NHS, 15.6% people reported mainly positive experiences, 25% mixed, and 59.4% mainly negative. Of those who were out as non-binary within private services, 60% reported mainly positive experiences, with 20% having mixed experiences, and 20% mainly negative. As discussed in section 4, the higher number of people presenting as binary at private clinics could be due to having more to lose from being denied treatment, despite our results here tell us that non-binary people have better experiences within private clinics. It may be the case here that the NHS' poor reputation in addressing non-binary issues within healthcare has an ongoing negative impact on the choices of non-binary people who are able to access private care.

Sample answers from those who were out as non-binary within NHS services include:

*“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 unless I “transition properly” and take testosterone which I did not want”*

*“Initially I was told that I would not be endorsed for any treatment unless I present as a binary-identified person and follow a prescribed (binary) treatment pathway. I was referred by the GIC to a cognitive behavioural therapist and blocked from seeing GIC clinicians during this time”.*

*“Told I cannot be helped and not to come back”*

Sample answers from those were out as non-binary within private services include:

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<sup>12</sup> Current waiting times can be found at <http://uktrans.info/attachments/article/341/patientpopulation-apr15.pdf>

<sup>13</sup> Count Me In Study

<sup>14</sup> NUS, Beyond the Straight and Narrow, available at <http://www.nus.org.uk/global/lgbt-research.pdf>

*“I felt listened to, understood, and respected”*

*“The fact that I was non-binary was never a problem”*

*“Expensive, but worth it”*

## 6 Self medication

Self-medication is the practice of using medicine without medical supervision to treat one’s own ailment. In the context of trans people, self-medication usually refers to the use of hormone replacement therapy without prescription or approval from a licensed clinician or pharmacist.

With the demand for NHS Gender Identity Services far exceeding supply, many non-binary people self-medicate due to a combination of long waiting times for services, a binary-focused treatment pathway which excludes non-binary people, and the drawn out testing process including ‘real life experience’ which forces trans and non-binary people to conform to binary norms of gender in order to receive treatment<sup>15</sup> (see section 3.2). Some respondents also told us they self-medicated in order to try HRT without needing to commit to it long term.

20% of respondents had self-medicated, while 15% of respondents chose not to say whether they had self-medicated or not. Of those respondents who had self-medicated, 72.7% reported a positive experience of self-medication, while 27.3% of respondents reported a mixed experience. **Not one respondent who disclosed that they had self-medicated reported a negative experience.** Reasons listed for undergoing self-medication were:

*“I trust myself more than the doctors”*

*“I felt that I did not need permission from a doctor to take testosterone although I understand the necessity of having an endocrinologist’s opinion”*

*“I was aware the NHS would take months or years before prescribing anything”*

*“I distrusted medical gatekeepers so I decided to take my healthcare into my own hands”*

*“I was frustrated with the long wait (3 years) and extremely dysphoric so a friend gave me some of his testosterone gel”*

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<sup>15</sup> ‘Was refused transition treatment for being lesbian, riding motorcycles, and not wearing skirts and heels to appointments’. Many more examples can be seen at <http://actionfortranshealth.org.uk/2014/10/20/transdocfail-moving-forward-with-a-new-non-binary-protocol/> and via #transdocfail on twitter

Whilst the RCPsych Good Practice Guidelines for Adults with Gender Dysphoria encourages GPs to offer bridging prescriptions to trans people who are self-medicating, the number of GPs actually offering this service is very low. As the guidelines allow for bridging medications as a harm reduction measure, it is disappointing that many GPs do not feel comfortable providing this service.

Similarly, GPs are able to provide blood tests to trans people who are self-medicating. Yet in our experience in trans advocacy, many GPs do not offer this service out of fear that it may “encourage” patients to engage in risky behaviour. We feel that whilst ‘official’ treatments remain inaccessible to many non-binary people, non-binary people will choose to self-medicate. This is because the risk of not undergoing HRT often feels greater in terms of depression and suicidal ideation than the risks associated with self-medication, which feel more remote and intangible. **We believe self-medication requires a harm reduction strategy, and that GPs and other health professionals should act in non-binary patients’ interests by monitoring bloods and providing bridging medications to those trans people who are self-medicating.**

## 7 Intersections

We held in depth interviews with non-binary people from under-represented groups. These included non-binary people of colour (see section 7.1), disabled non-binary people (see section 7.2), intersex non-binary people (see section 7.3) and non-binary people who experience transmisogyny (see section 7.4).

### 7.1 Race

A significant theme in our interviews with non-binary people of colour<sup>16</sup> was how that the binary gender system is a specifically Western European concept, and that clinicians were not aware of this history:

*“The gender binary is a European concept, those colonisers exported it across the globe... the psychiatrist seemed really confused why I was talking about my gender in this way as if it wasn’t relevant”*

Some felt that this history had implications for how they identified:

*“What it means to be a black woman is different to what it means to be a white woman. Being black, in a European country, I always felt that I could never*

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<sup>16</sup> This is the term that our interviewees preferred.

*live up to what I know see as white womanhood. I claim non-binary as well as woman as words that describe as a statement of not fitting into this model.”*

The lack of knowledge on clinicians' parts regarding the history of the binary gender system's relationship with white supremacy is concerning as it may mean that people of colour are less likely to trust clinicians with clinically relevant information due to clinicians' lack of cultural understanding. Further, the lack of knowledge of this history may mean that clinicians unknowingly contribute to its re-enactment. Whilst our interviewees did not discuss specific acts of racism occurring between clinicians and patients, **they did understand and describe the lack of non-binary inclusion within healthcare protocols as an act of racism as it disproportionately affects people of colour.**

## 7.2 Disability

Barriers accessing transition related healthcare due to disability was the fourth highest concern regarding treatment after fear of treatment denial, uncertainty over what treatments are desired, and concerns of societal reactions. This is consistent with the widespread understanding within the trans community that many trans people are also disabled. Some participants felt that their disability was a significant factor informing their identity:

*“I find it really difficult to come to terms with my agender-ness... People who use wheelchairs are constantly seen as genderless, and I felt like I was selling out saying that gender didn't apply to me. It didn't help that my psych basically straight out asked if [my non-binary identity] was because I'm disabled.”*

Whereas others had identified barriers to accessing healthcare through the GICs not addressing their specific access needs:

*“My mobility problems mean that I found it really difficult to get to the GIC. By the time I got there I was in a lot of pain and at the end of my tether. Then to be interrogated about being genderqueer... I couldn't cope. I ended up self-medicating cause it wasn't worth going to the GIC”.*

*“I have Asperger's and find not knowing what is going on with my transition very unsettling. I cannot use phones but the GIC is so bad at sending letters I feel I am always in the dark”.*

We recommend that an impact assessment is undertaken to see how **disabled people are disproportionately negatively impacted within trans healthcare**. We also would recommend the establishment of **local gender identity services** (or “satellite” services) to reduce travel times, and a **review of communication processes** between clinics and patients.

### 7.3 Intersex

Intersex is an umbrella term, describing states of being whereby a person's physical sex falls between or beyond that considered archetypically male or female. An intersex person may have hormones at different levels from a male or female person, ambiguous genitalia, or a different chromosomal make-up to dyadic (non-intersex) people. Intersex people with ambiguous genitalia often have their genitals operated on at birth to give the appearance of dyadic sex and many intersex people may undergo some 'corrective' hormone treatment during their lives. Some intersex adults wish to undergo HRT or surgeries to return to what feels natural to them. Other intersex people are simply trans in the same way that dyadic people can be trans.

Despite the large crossover between intersex and trans issues, our participants felt that **clinicians did not understand intersex people's healthcare needs:**

*"Frankly, the psych had no idea what intersex was"*

*"I am an intersex person with a non-binary gender identity. [Clinicians] refused to believe that I had undergone RLE because despite changing my pronouns from she to they, I had not changed my name. I don't see why my name has to change just because [Clinician] thinks it's a 'female name'. I'm intersex and non-binary, I have never been female."*

### 7.4 Transmisogyny

Transmisogyny is a specific form of oppression defined as the confluence of transphobia and misogyny which affects trans women and some non-binary people who were assigned male or intersex at birth. Trans people assigned male or intersex at birth were a minority in our sample (32.5% and 0.8%, respectively), and are often anecdotally seen to be less likely to define as non-binary than those who are assigned female at birth. However this could potentially be caused by a lack of visibility of non-binary people assigned male at birth. One interviewee discussed the lack of visibility of non-binary people who were assigned male at birth in depth:

*"I am a genderqueer person who was coercively assigned male at birth. I think there is this widespread idea that non-binary people were all assigned female, and that assigned male people like myself are simply 'not doing it right'. This goes for both the non-binary community and GICs, I feel like my identity is being constantly policed"*



*“I feel like there is a lack of visibility of amab non-binary people within the community. I think this lack of visibility, as well as misogyny from nonbinary afab people, and the dangers of being amab and living visibly between genders, pushes amab non-binary people out of the non-binary community and towards a community of trans women. I’m not saying it changes how they identify, but that they often have more interests in common with trans women than they do with afab non-binary people”.*

We found that many non-binary people who had been assigned male at birth had experiences of transmisogyny when accessing healthcare. As one participant said:

*“I was told [by the GIC] that we don’t support shemales here”*

## **8 Conclusions: the informed consent model of trans healthcare**

Within this report, we have addressed the key problems facing non-binary people when accessing transition related healthcare. These include, but are not limited to; a pathologising and binary-focussed diagnostic evaluation, an inflexible binary-centred pathway, and a lack of understanding for non-binary people’s healthcare needs. These concerns, when applied to a healthcare system which is often characterised by patients as having significant problems with staffing resilience, poor communication between clinicians and patients, and long delays in accessing treatment, often leads to non-binary patients being excluded in some form from accessing prompt and appropriate treatment. This can have a long term mental health impact on non-binary patients and drives many to self-medicate.

Within this report we have also highlighted key opportunities whereby service provision can be improved. These include: a move away from pathologising diagnostic evaluations, increased flexibility, the need for greater training, and changes to communication processes between clinicians and patients. We believe that these recommendations broadly fit within the informed consent approach to trans healthcare, and that adopting this model of healthcare has the potential to lead to a significant improvement in patient experience as well as potential cost savings.

The **informed consent** model of trans healthcare exists when a patient who is informed of the possible positive and negative consequences of treatment may choose to undergo said treatment of their own responsibility. It stands in contrast to the current model of trans healthcare whereby a patient must successfully jump through several diagnostic hoops in order to receive treatment. The informed consent model of trans healthcare is successfully adopted by several clinics in the

United States<sup>17</sup>, and is consistent with the current WPATH Standard of Care<sup>18</sup>. **The main difference between the current model and the informed consent model is the emphasis it places on harm reduction and informed consent as the threshold for initiating treatment, whereas current practice emphasizes the role of mental health practitioners as gatekeepers and assessors and sets up an arbitrary number of meetings and steps which must be fulfilled before treatment can commence.**

We believe that adopting the informed consent model of trans healthcare can address many of the concerns raised by non-binary patients, and is consistent with the recommendations we have made elsewhere in this report. It allows clinicians to be more flexible in their approach to healthcare provision, allowing less complicated cases to be processed quicker and so reduce waiting times. It also resolves the issue of all non-binary people being seen automatically as complex cases and instead allows for treatment to be appropriate and person centred. As a model which emphasizes consent to various treatment options, rather than a binary centred diagnostic model, it holds significant promise in improving the non-binary patient experience.

## 9 Recommendations

1. That gender identity monitoring is implemented across NHS services to allow for data on trans and non-binary experiences and healthcare inequalities can be collected.
2. Changing diagnostic criteria such that the patient consistently identifying a particular treatment as desirable is used instead of the words that the patient uses to describe their identity.
3. Gender identity clinics should endeavour to ensure that clear and accessible information regarding treatment options are made available to service users.
4. Ceasing the requirement for RLE as part of diagnostic evaluation. Instead, ensuring that the service user has good support systems in place and feels empowered to choose to be out in situations where they would like to be and it where it would be beneficial, to them, for example, with their GP, within community support spaces and within their workplace's LGBT network.
5. Should RLE exist, it should be made more flexible to account for non-binary people's needs and be measured in more flexible ways.

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<sup>17</sup> Such as the Callen Lorde Community Health Center, 2000, 2011; Fenway Community Health Transgender Health Program, 2007; Tom Waddell Health Center, 2006

<sup>18</sup> See [http://www.wpath.org/uploaded\\_files/140/files/IJT%20SOC,%20V7.pdf](http://www.wpath.org/uploaded_files/140/files/IJT%20SOC,%20V7.pdf)

6. There is urgent need for gender identity healthcare providers to implement significant culture changes in order to build trust with non-binary patients so they feel comfortable being 'out' within a clinical setting. Part of this involves following the recommendations in this report, but clinicians and administrative need to be trained in non-binary issues.
7. A more flexible approach to treatment options is required in order to fit non-binary patients who fall outside of the traditional binary treatment model, i.e. allowing a service user to access top surgery without having HRT first.
8. GPs should follow the RCPsych Good Practice Guidelines for Adults with Gender Dysphoria and routinely offer bridging prescriptions to trans people who are self-medicating.
9. GPs should routinely provide blood tests to trans people who are self-medicating.
10. Clinicians and administrative staff at GICs should undertake cultural competency training for issues around race, misogyny, non-binary, intersex and disability.
11. That an impact assessment is undertaken to see how disabled people are disproportionately negatively impacted within trans healthcare.
12. The establishment of local gender identity services (or "satellite" services) to reduce travel times.
13. A review of GICs communication processes between clinics and patients to take place, and where necessary, extra staff taken on.

## 10 Terminology

**Androgyne:** a non-binary identity associated with androgyny.

**Bigender:** someone who identifies with two genders at the same time.

**Demi-boy:** a non-binary identity whereby someone is partly a boy and partly something else.

**Demi-girl:** a non-binary identity whereby someone is partly a girl and partly something else

**Gender:** a person's internal sense of self as a man, woman, or something else.

**Genderqueer:** an umbrella term for various identities outside of man and woman; and/or; a queer gender.

**Gender Fluid:** someone whose gender identity is fluid or shifting.

**Gender Identity Clinic:** a healthcare clinic specialising in trans healthcare. A trans person will usually need to attend a Gender Identity Clinic before accessing gender affirming treatments such as hormone replacement therapy or surgeries.

**GIC:** see **Gender Identity Clinic**

**Gender Recognition Act:** A UK Act of Parliament which allows trans people to change their legal gender from one binary gender to another.

**Hormone Replacement Therapy:** the therapeutic use of hormones such as oestrogen and testosterone. In the trans healthcare context, cross-sex hormone replacement therapy is used to produce physical changes such as voice deepening and body hair growth (testosterone) or fat redistribution, breast growth, and a reduction in body hair growth (oestrogen).

**HRT:** see **Hormone Replacement Therapy**

**Informed consent:** a model of trans healthcare which emphasises a patient's informed consent to treatment. This model is seen by many trans people to be less pathologising than the current model.

**Intersex:** an umbrella term of states of being whereby a person's physical sex falls between or beyond that considered archetypically male or female.

**Non-binary:** an umbrella term of gender identities that fall between or beyond the gender binary of man/woman.

**Polygender:** someone who identifies as several genders at once

**Polygender Fluid:** someone whose gender is fluid between several different genders

**Pronoun:** a word that people use to refer to others without saying their name, i.e. he/his, she/hers, they/theirs, ze/hir, etc.

**Real Life Experience:** A period of one to two years where a trans patient lives in their acquired gender role before being allowed to receive treatment for gender dysphoria.

**RLE:** see **Real Life Experience**

**Sex:** sets of physical characteristics based around chromosomal, hormonal and reproductive functions, i.e. male, female, intersex

**Trans / Trans\*:** an umbrella term to describe anyone whose gender identity does not match the gender that they were assigned at birth.

**Transmisogyny:** the confluence of transphobia and misogyny which oppresses trans women and some non-binary people who were assigned either male or intersex at birth.

**Trans man:** a man who is trans. Usually this means a man who was assigned female or intersex at birth.

**Trans woman:** a woman who is trans. Usually this means a woman who was assigned male or intersex at birth.