

# NHS GENDER IDENTITY SERVICES FOR ADULTS - SERVICE SPECIFICATIONS CONSULTATION

## Introduction

This document consists of our analysis and response to the ongoing consultation of the NHS Gender Identity Services Service Specification and to the changes discussed within both the consultation guidance and the service specification documents.

We highlight a number of changes that we believe are improvements of the current situation, but also draw attention to and make recommendations around a number of concerns we have around the new specifications.

While we are pleased that the draft service specifications have been published, we feel that these have not sufficiently addressed a number of issues with the current arrangements for gender identity services, and, in some cases, introduce new issues which must be resolved.

We also recommend informed consent models, which would be a great improvement for many trans people, and would also reduce waiting times and resources required to provide these services.

The consultation guidance and draft service specification documents can be found [on the NHS England consultations site](#).



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## General

- We are very pleased to note the requirement for providers not to engage in any way with reparative therapy.
- We appreciate that appointments and assessments can take place over the internet as an accessibility tool. We would still like to see a more firm commitment towards national procurement of services local to the service users to help with the costs and difficulty of travelling for those who can or would prefer to travel.
- We understand that the scope of this consultation does not include treatments and interventions not currently commissioned by the NHS. It is, however, vital that this is an issue that be addressed. There are a number of procedures that would greatly benefit the health and wellbeing of trans people; it is vital that the NHS offer these.
- Similarly there are procedures that currently can be obtained on the NHS, but only with great effort on the part of the patient, because they are uncommon procedures. It's important that patients be able to undertake the interventions that are most important to them, even if they're seemingly "atypical" to what most other trans people would desire. This is particularly relevant where treatment of nonbinary people is included, as well as where identities that are not rooted in modern western culture are concerned.
- Clarity and consistency in the requirements for physical examinations is important. Given the issues that have arisen in the past with regards to physical examination, we do appreciate that this issue is being addressed. We expect that all practitioners suggesting or undertaking a physical examination be held to a standard of perfection in treating people with respect and respecting a person's autonomy. Under no circumstances should a person be required to undergo a physical examination without a friend, family member or advocate in attendance if they wish, regardless of impartiality - even if for no other reason than that of comfort.
- The under representation of BAME people is, in part, due to the discrimination and treatment that members of these communities face within health services in general (as evidenced by the documents referenced within the consultation guidance). As such, it is not enough to simply say "there must be measures in place" - these measures must be considered in consultation with the trans and nonbinary BAME communities and explicitly outlined.

## Referral Process

### Accessibility

- As stated in the consultation documents, while we realise that anyone should be able to register with a GP- regardless of whether they are homeless, a vulnerable migrant, of no fixed address or a sex worker- and that proof of identity/address is not required to register with a GP, it must be acknowledged that many GPs and trusts do require this information to register. A high proportion of trans people do fall into one or more of these categories, and so presenting this barrier to accessing gender identity services is indirectly discriminatory. There must be support in place for allowing people from these groups to access services, without deferring that responsibility down to local GPs.

### Self-referral

- We need to be moving towards a self-referral model instead of referral via GP - there is no reason for GPs to necessarily be involved in the referral process, and this model has worked successfully elsewhere (including in Scotland). This would not only solve the aforementioned issues (of accessibility to services), but would help prevent a GP's personal opinion or ignorance on trans issues from becoming a barrier or delaying a patient's referral.

### Acute conditions

- We find it very concerning that the service specification not only includes mechanisms to delay those with mental and physical health issues access to services which may help to alleviate these issues, but furthermore acknowledges and accepts that this is the case, and justifies it as non-discriminatory.
- In the cases of both physical and mental health conditions, what is considered "acute" is unclear and left open to interpretation.
- Preventing people access to gender identity services on the basis of their having an acute condition - particularly with regards to mental health - may serve in many cases to exacerbate the situation. This can lead to services preventing people access to the care which may alleviate their pain. We have encountered many situations where this has been the case, and where access to services and interventions has significantly helped with a patient's acute mental health situation.
- Similarly, we know that the mental state resulting from gender dysphoria can often lead patients into alcohol and substance misuse as a coping mechanism. While the risk factors of this should be discussed with the

patient in cases where this is the situation, this must not be a barrier to treatment.

### **Age and GIDS**

- Outlining the ages at which referrals will be accepted to various gender identity services (including GIDS) does work to improve consistency across clinics, as well as work toward preventing referrals to a clinic which will only see a person for a brief period of time based on their age.
- The notion of keeping an individual up to age 20 in GIDS based on “emotional or psychosocial factors” is condescending and stigmatising at best. This should move towards an informed consent approach, in which we understand that patients have an awareness of their own needs and emotional state. This would give patients the autonomy to decide whether or not the transfer into adult service would be suitable for them. The document remains unclear as to who the decision maker in these cases is, and we are deeply concerned that the specialist teams and clinicians themselves could make this decision on behalf of the patient.

### **Intersex issues**

- The service specification outlines an exclusion for people whose presentation “primarily relates to intersex conditions”. We’re wary of what constitutes “primarily relating to an intersex condition”.
- We feel it is imperative that it is made clear who is given authority when deciding whether an individual’s presentation is “primarily relating to intersex conditions”. We would expect that to be based on the patient’s own understanding of their presentation, rather than based on the interpretation of a practitioner.
- There is a large overlap of intersex individuals who also identify as trans - generally, who have been assigned a sex and gender at birth and raised in such a role, but who do not identify that way. This is accepted as a transition and these identities as trans and/or nonbinary people are valid.
- The GICs have a history of not treating people who are intersex, regardless of how being intersex affects their identity, anatomy or presentation. The GICs, however, are often the best placed service to help intersex people who identify as trans. While a standard path of care may not be appropriate for intersex people (due to endocrinological or anatomical contraindications), the GIC endocrinologists and surgeons have a very similar experience and knowledge sphere as those who would treat intersex people in other

contexts, but with a crucial contextual understanding of trans identities.

- It is important that intersex people have access to gender identity services given the notable overlap of intersex people who identify as trans and nonbinary.

## **Assessment Process**

### **Informed consent model**

- At present, psychological, emotional and social factors are being given far too weight in the treatment process.
- Barring particularly exceptional circumstances, a patient is always best placed to understand their own needs and the factors which weigh into their decision, as well as the interactions with their gender dysphoria.
- Formal “assessment” of these factors - as opposed to consultation with the patient - is a denial of patient autonomy. We need a model of informed consent in which the patient makes the final decision in consultation with a medical professional. This must be patient led and any decisions or conclusions must ultimately be the patient’s own. This model of informed consent has proved to be successful in clinics throughout the world - as an example, Planned Parenthood in America, which uses a model of informed consent and patient decision making with guidance from a medical professional. Essentially, what is referred to as “shared decision making” is still clinician led and centred in many ways, whereas this must rest with the patient.
- This informed consent approach must be taken in all aspects of the gender identity services, and regardless of what interventions a patient wishes to undertake.
- For patients confident in their transition needs (such as HRT, hair removal and surgical interventions), an informed consent model that is adequately implemented would mean a parallel pathway where much of this is undertaken by the GP and local specialists, with referrals to surgeons and other specialists by the GP where necessary. For many patients, this creates a more straightforward and less resource intensive pathway.

### **Family members**

- Clarification that a clinic must not require family members, spouses or partners to attend appointments- and especially give permission- helps to maintain consistency between clinics, and helps to maintain

patient autonomy. We are concerned that a clinician is still permitted to request the attendance of a family member with justification. Where this occurs, the decision must be the patient's as to whether the family member can and will attend, and the patient must not feel pressured into allowing this. A patient refusing to bring a family member to a clinic must not influence or affect their treatment.

### **Gender presentation and nonbinary people**

- At present, it is not uncommon that nonbinary people and people whose presentation is not conventional for their gender undergo a more rigorous assessment, or have to justify their presentation in order to access services. We are concerned that while equitable access to services and interventions is required once diagnosed, this does not necessarily mean that assessment for these individuals will not continue to indirectly act as a barrier or additional complication in accessing treatments and services in the first place. This must not be the case, particularly in any situation where the aforementioned informed consent model is not implemented.

## **HRT**

### **Preferred model of arrangements: “D”**

- While we go on to look at and prefer models of prescribing as discussed in the consultation, we do feel that these models all centralise on the concept of assessments by the GICs. A good implementation of an informed consent model would mean that local GPs could directly refer to the local specialist who could undertake a readiness consultation with the patient directly to determine potential medical contraindications prior to starting HRT, removing the need for assessment at a GIC level.
- The following discussion regarding which model best resolves the issues with the current arrangements is undertaken in spite of the fact that we prefer an informed consent model to those presented.
- With regards to prescribing hormone treatments, we prefer model “D”. We would argue that this model allows for the most efficient treatment of trans people in an area without requiring excessive amounts of travel. We would, again, push for a model of assessment under informed consent, rather than the specialist team forming a medical opinion based on arbitrary factors and stigma.
- Furthermore, in engaging with option “D”, we continue to be concerned that travel to these specialists may not be accessible for all. We push

for additional considerations to be made with regards to accessibility and travel.

- We are equally concerned that the local specialists will have long waiting times for access in some areas. In these situations, should the local specialist take more than 18 weeks to undertake prescribing, we feel the GP should undertake prescribing until the local specialist can take over (whether on recommendation from the specialist team or in a bridging capacity).
- In an area where the local specialist routinely cannot see a patient within 18 weeks, we would advise that additional local specialists are needed. We're aware that this has been acknowledged, but this consideration must be made explicit from the outset.

### **Bridging prescriptions and self-medication**

- In many cases at present when an individual who is self-medicating approaches a GP, they are told they should immediately stop until their assessment and recommendation from the specialist team is complete. It must be explicit that this response will be replaced with the commencement of bridging prescriptions and the appropriate monitoring. A person who is self-medicating is not going to stop because they are told to do so, however to continue to do so without monitoring is dangerous, as is the obtaining of medications from unreliable or unproven sources (as is quoted by many GPs). However, stopping and restarting HRT is damaging as well, and the appropriate action here is to make the situation as safe as possible.
- In any case, and particularly in any outcome in which the specialist team continues to undertake assessments for hormone therapy, there must be explicit guidance with regards to the role of bridging prescriptions. In a situation where assessments continue to be necessary for access to HRT, bridging prescriptions for those who are awaiting assessment must be made available, as access to hormone therapy should be a right of all trans people. Furthermore, a lack of bridging prescriptions in these situations will often lead to an individual self-medicating. In the model of prescribing preferred (“D”), the role of undertaking bridging prescriptions can be performed by the local specialist.

### **Ensuring option “D” meets the 18 week referral-to-treatment criteria**

- Essentially, we feel a pathway which includes bridging prescriptions and ensures the patient obtains treatment as efficiently as possible would be implemented as follows:
  - A referral to the specialist team is made by the GP.

- If a patient is self-medicating, or requests bridging prescriptions, they should be seen by the local specialist as soon as possible, who should undertake issuing bridging prescriptions.
- If the local specialist cannot see the patient within 18 weeks, the GP should undertake prescribing until the patient can be seen by the local specialist.
- Regardless of bridging prescriptions, when the patient is ready for HRT after consulting with the specialist team, a recommendation and referral to the local specialist should be made.
- If the local specialist cannot see the patient within 18 weeks, the GP should act on the recommendation until the patient can be seen by the local specialist.

### **The other options**

- We have also considered the impact of options A-C in our recommendations above:
  - We would highlight that option “A”, which represents the current arrangements, has not been working well for some time, as many GPs are overly cautious to prescribe (even with recommendations from the specialist team), particularly because the prescriptions are off-label. Furthermore, in some cases, GPs refuse to even acknowledge the treatment that trans people need or treat them with respect, generally due to a lack of training, awareness or for personal reasons of prejudice.
  - Option “B” maintains the same problems, only slightly mitigating by giving the GP more time to prepare for when they may have to take over from the specialist team, which while may alleviate the concerns in some cases, does not resolve the ongoing issues.
  - Option “C” leaves us concerned that, where the GICs currently have long wait and administration times, any changes or review appointments will take too much time to be effective. It also increases travel costs and concerns for those with accessibility issues around travelling, since both monitoring and prescribing will be undertaken by the clinics. Furthermore, GPs’ current apprehensions with regards to prescription would continue to be an unaddressed issue past the 1 year point.

## GRS and other surgeries

### Referrals

- The documentation states that referral for GRS must come from a GIC and cannot come from a private clinic or private GIC. We acknowledge the logic behind this, however we feel the NHS should be working in cooperation with private GICs. Doing so would ease the load on the Gender Identity Clinics as well as helping with costs to the NHS - this includes accepting GRS referrals from private GICs. Furthermore, GRS is an issue of body autonomy, which everyone has a right to. We feel that any medical professional should be able to engage with this right and refer for GRS where appropriate - including GPs.
- For the same reasons of body autonomy, we feel that the requirement for a second opinion- medical or otherwise - being required for referral for GRS is excessive. While we understand that surgeries are a complex undertaking, in line with our call for informed consent, we feel the patient is, again, best placed to make decisions with regards to their body and treatment and should be given more power in the decision making process.
- One medical “opinion” should not be required in the first instance, as we acknowledge that the patient is best place to know that they need surgery, and the patient and the surgeon together can assess the readiness for surgery (as below) - let alone two opinions.
- There are circumstances in which it would be useful for a GP to be able to make a referral for GRS, particularly in cases where a patient already has a diagnosis and needs no other treatment or assessment - these patients should not need to engage with additional assessment or delay from a GIC in order to access surgeries that they need.
- In line with these points, we support in principle the proposal of the Clinical Reference Group to remove the need of a medical practitioner to assess readiness for surgery. We agree that readiness can be assessed by the surgeon after referral, however we would like any assessment for readiness of surgery to be undertaken inline with the informed consent model above.
- While we do believe it is an improvement that a surgeon will assess the risk with regards to high BMI in surgical patients, we would, again, call for this follow an informed consent model in which the patient assesses the risk to theirself, with the consultation of the surgeon, to ensure that this is undertaken based on actual medical data, rather than stigma and arbitrary guidelines.

## **Lived experience**

- We still reject the need for a patient to have spent 12 months living in the acquired gender role in order to undertake GRS.
- The statement that this requirement is to “prepare and support the individual to cope with the profound consequences of surgery” is nonsense. This is a patronising approach - it implies that trans people need to be taught the consequences of transition. Furthermore, we note that the perceived consequences of surgery in this context are not consequences of surgery itself.
- In addition, it is not possible to quantify what a nonbinary person living in their acquired gender role would look or feel like, and while this is noted in the document, the existence of this requirement and the note about taking into account lived experience prior to referral suggest that there is a way for clinicians to judge if this requirement has been fulfilled. This contradicts the requirement for nonbinary people to equitable access to services.

## **Corrective procedures**

- The guideline that states that corrective surgical procedures for a poor outcome that is recognised more than 18 months after surgery is concerning. Complications can arise at any time following surgery, and it is important that these be dealt with quickly and efficiently.