

# Response ID ANON-U3E4-AEEG-K

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## About you

### What is your name?

**Name:**

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### What is your organisation?

**Organisation:**

UK Trans Info

### Job title?

**Job title:**

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## Subject of response

### Are you responding to a:

Service specification

## Service specification

### Please indicate which service specification you would like to comment on:

Gender identity services Service Specification

## Service specification - Questions

### In your view, what would be the effect of the proposed changes on the service?

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These changes do provide a significant improvement over the current interim specification. In particular we welcome the inclusion of gamete storage, breast augmentation, thyroid chondroplasty and phonosurgery in the document. However we are very concerned by the exclusion of facial feminisation/masculinisation surgery which we believe and the WPATH SOC states "can have a radical and permanent effect on their quality of life, and therefore is much more medically necessary than for somebody without gender dysphoria" .

While we welcome the specific inclusion of non-binary people in these documents, we believe that these documents are dangerous for non-binary people and illegally discriminate against them. They will force many non-binary people to lie about their gender to clinicians and pretend to be a trans man or a trans woman in order to access the treatment they require. This is already happening in almost half of cases – see <http://uktrans.info/attachments/article/378/ATH-Non-Binary-Survey-Results.pdf> More details provided below.

Section 1.1.5 describes three main health inequalities that this specification is trying to resolve. These are inequity of access to the Gender Identity pathway across England; differences in provision of services by different service providers; and differences in interpretation of standards of care resulting in differences in treatment provision by different service providers. We believe that this service specification does not go far enough to reduce these inequalities. Specifically:

1) There needs to be more consistency about how patients are assessed. For example Charing Cross and Northampton will consider prescribing hormone therapy on the second appointment, but Exeter will not consider it until the fifth and Sheffield until the sixth. Nottingham have a unique method on their third appointment where they insist the patient must bring along a friend or family member to the appointment, which is an outright breach of patient privacy, confidentiality and autonomy. These inconsistencies should be greatly reduced by having the service specification spell out in greater detail what the assessment process should look like.

2) The service specification needs to be clear as to whether GICs will be commissioned on a block grant per year or set amount per patient basis, and should produce a standard contract. Currently there is a mixture of the two approaches leading to inequity between what different GICs are able to afford to provide.

### What further changes, if any do you think need to be made to this document?

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We like the fact that the service spec looks at a range of outcomes, including social and physical wellbeing, as well as mental. We think this should be reflected in the earlier introductory text, which at present is very focused on alleviating personal psychological distress linked to dysphoria, and doesn't address wider issues such as improved social functioning.

Section 1.1.2 suggests that agender people will only need gender neutralising treatments and also implies that people who aren't agender will not need gender neutralising treatments. Neither of these statements are correct, and the full array of treatments should be open to all.

The Epidemiology section 1.1.4 should also note that an analysis of all available research by Practical Androgyny showed that 0.4% of the population has a non-binary gender (taken in this report to mean that their gender "would not be adequately represented by an either/or choice between 'man' or 'woman'"). Source: <http://practicalandrogyny.com/2014/12/16/how-many-people-in-the-uk-are-nonbinary/>

1.1.6 should be updated as Nottingham Gender Clinic has changed name and address.

Section 3.3.2 i – By forbidding GICs from prescribing medication and associated monitoring tests it is increasing inequalities, risking patients being unable to start treatment and in some cases risking patients treatment being stopped if they move areas. Many GPs refuse to prescribe medication that has been recommended by GICs, and there are at least two towns in England where there are zero GPs willing to do these prescriptions. In addition there have been occasions where CCGs have 'red-listed' certain medications that are used for the treatment of gender dysphoria, which has meant that GPs have been unable to issue prescriptions. GICs must be able and required to prescribe medication where GPs are unwilling or unable to do so as a short-term measure until an alternative solution can be found.

Section 3.3.2 ii – There is no justification for forbidding facial feminising and masculinising surgery, which is an absolutely essential and clinically necessary treatment for some trans and non-binary people. FFS/FMS can sometimes have a much larger impact in reducing gender dysphoria than any other treatment, and also have practical benefits on the patient's ability to engage with the wider world. Page 58 of the WPATH Standards of Care states "Although it may be much easier to see a phalloplasty or a vaginoplasty as an intervention to end lifelong suffering, for certain patients an intervention like a reduction rhinoplasty can have a radical and permanent effect on their quality of life, and therefore is much more medically necessary than for somebody without gender dysphoria." In our view these procedures must be allowed along similar lines as feminising chest surgery and phonosurgery.

Section 3.4.1 – There should be explicit reference that psychological therapies must not include any form of "conversion therapy" (eg attempts to convince patients that they are not trans or to 'cure' them). In addition there must be no gender stereotyping from clinicians. For instance, a trans man should not have to have a stereotypically heterosexual masculine hair cut or clothing. We also want to see an end to binary-centric models of counselling and therapy which seek to push non-binary individuals towards binary forms of gender identity and expression.

Section 3.4.3 - We strongly disagree that where the provider, SGIS and service user all agree that further facial hair removal is both necessary and likely to be effective it should be arbitrarily limited by funding limits. Further blocks of photoepilation or electrolysis should be provided until treatment is no longer clinically justified.

Section 3.4.4 xv – Chest surgery for trans women and non-binary people should be available after "18 months of a therapeutic level of feminising hormones" as stated in the UKGPG, not "at least 24 months of adequate feminising hormone therapy (to include adequate suppression of testosterone)"

Section 3.4.4 xvii – We very strongly object to chest surgery for non-binary and non-gendered people being described as "a complex clinical judgment" and we very strongly object to this paragraph only saying that it "may" be provided, rather than it "will" be provided as for trans men and trans women. This is an absolutely discriminatory and dangerous policy that will undermine any trust non-binary people have in the system and lead to non-binary people continuing to lie to clinicians and presenting with a binary gender in order to obtain the treatment they need. Also this does not fit in with the specialised services commissioning rule that says services will only be provided where they can be provided to all patients in the group. Chest surgery for non-binary and non-gendered people must be provided on the same basis as it is provided to trans men and trans women. This will be subject to legal challenge if left unchanged.

Section 3.4.5 – This section only mentions trans women and trans men, and does not provide GRS for non-binary and non-gendered people. This is an absolutely discriminatory and dangerous policy that will undermine any trust non-binary people have in the system and lead to non-binary people continuing to lie to clinicians and presenting with a binary gender in order to obtain the treatment they need. Also this does not fit in with the specialised services commissioning rule that says services will only be provided where they can be provided to all patients in the group. GRS for non-binary and non-gendered people should be provided on the same basis as it is provided to trans men and trans women. This will be subject to legal challenge if left unchanged.

Section 3.4.5 ix – Currently surgeons are imposing BMI limits and (for some surgeons) waist size limits on GRS. These limits vary from surgeon to surgeon. If there is clinical justification for these limitations then they should be made explicit in this service specification or else abolished. Also it must be noted that continued refusal of surgery due to BMI limitations could be subject to legal challenge as a breach of Article 8 (right to respect for private and family life) of the European Convention on Human Rights.

3.4.8 xiii - We very strongly object to thyroid chondroplasty for non-binary and non-gendered people being described as "a complex clinical judgment" and we very strongly object to this paragraph only saying that it "may" be provided, rather than it "will" be provided as for trans women. This is an absolutely discriminatory and dangerous policy that will undermine any trust non-binary people have in the system and lead to non-binary people continuing to lie to clinicians and presenting with a binary gender in order to obtain the treatment they need. Also this does not fit in with the specialised services commissioning rule that says services will only be provided where they can be provided to all patients in the group. Thyroid Chondroplasty for non-binary and non-gendered people must be provided on the same basis as it is provided to trans women. This will be subject to legal challenge if left unchanged.

We do not think the documents take enough account of the fact that total laparoscopic hysterectomy with salpingo-oophorectomy is a standard procedure, which most gynaecology units can provide, and which most GPs comfortably make referrals for on a regular basis. In addition, as the commissioning document says, many trans men and non-binary people end up needing the procedure for clinical reasons (e.g. heavy bleeding, pain) or for preventative reasons (e.g. they don't want smear tests/pelvic ultrasounds and are concerned about cancer) rather than for specifically dysphoric feelings. The document seems to imply all trans men

seeking such procedures should follow a specialist gender services pathway. We think GPs should be able refer trans men and non-binary people for these procedures at a local unit, exactly as they would for female patients, without requiring gender specialist approval (at present many GPs do but the situation is somewhat unclear and sometimes surgeons refuse the referral without GIC sign off). There doesn't seem to be any good reason to suggest that a female patient can take a rational decision in discussion with her GP to have this surgery, and a trans man cannot. It would certainly be discriminatory if the intention is to require that a trans man experiencing painful or distressing symptoms wait for a GIC appointment in order to be referred to a gynaecologist in a situation where a female patient could be directly referred.

**Are there any other considerations not reflected in the document that you wish to draw our attention to?**

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Given that gender identity services waiting lists are currently breaching 18 week referral to treatment legislation, we believe that explicit mention of this standard should be made in this document and it should be included as an outcome measure.

Bridging prescriptions (which are mentioned 3 times in the UKGPG and also discussed in the WPATH SOC) need to be explicitly dealt with in these documents to ensure that patients who are currently self-medicating or who are at risk of self-medicating are brought into a properly monitored prescription immediately, even if they are still on a waiting list. It must be made absolutely clear that when a GP contacts a GIC regarding a patient on the waiting list who is self medicating (or at risk of doing so) then the GIC must advise the GP on how to bring the patient onto a properly monitored bridging prescription immediately. Similarly, where a patient attends a GIC appointment and informs them that they are self-medicating, the GIC must recommend to the GP that the patient be immediately brought onto a properly monitored bridging prescription. Failure to do this leaves a vulnerable patient in an incredibly dangerous situation, breaches the UKGPG and could be considered negligence.

Given the incredibly high suicide rate in trans and non-binary people as acknowledged on page 8 of the draft commissioning policy, domain 1 (Preventing people from dying prematurely) should clearly be considered here. Where an active patient commits suicide their case should be fully reviewed (preferably by a previously uninvolved clinician) to look for anything that could have been done to further support the patient and any key learnings that can be made. An anonymised copy of the review should be made available to the SGIS CRG. Number of suicides from active patients should be an outcome measure.

GICs should accept patient self-referrals. We frequently hear from patients who have uncooperative or unknowledgeable GPs who refuse or delay referrals to GICs. GPs do not have the knowledge or training required to have a legitimate reason to refuse a referral to a GIC, so there is no need for their involvement. When a patient self-refers to a GIC, it can include consent for the GIC to contact the patient's GP for medical history details.

We strongly believe that the service specification should state that GICs must engage both with the NHS England Gender Identity Network, and also with local organisations and patients. Currently some choose to engage, and others don't.

There is no mention of how it should be handled where a patient has been discharged from the gender clinic (perhaps many years ago) or were previously treated privately but now wants to access treatments that were not previously available such as facial hair removal or thyroid chondroplasty. We believe many patients will be in this situation, and we believe that in many of these situations the GIC should be able to accept a letter from the patient (or patient's GP) requesting treatment be provided and process the referral for treatment without the need for the patient to be seen and reassessed at the GIC.

**Would you like to provide any final comments?**

Yes

**Final comments**

**Please provide final comments below:**

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This consultation should have lasted 12 weeks. When the initial draft was sent to the SGIS CRG Stakeholder group for initial consultation it was very clearly stated that opinions were not being sought on the length of the public consultation as it would definitely be a full 12 week consultation. In addition it has regularly been stated that 12 weeks is the 'gold standard' for consultations, and there must be good justification to reduce this. The consultations on the two SGIS documents are for a complete rewrite of the service spec and commissioning policy. The last consultation highlighted massive inadequacies to the point where the SGIS documents were the only ones to be refused. These incredibly complex documents have a high level of interest from the patient body, and a 30 day consultation is highly inadequate.