Response ID ANON-U3E4-AEZ2-K

Submitted on 2015-04-23 01:22:31.904084

About you

What is your name?

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Job title?

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Subject of response

Are you responding to a:

Clinical commissioning policy

Clinical commissioning policy

Please indicate which Clinical commissioning policy you would like to comment on:

Gender identity services Clinical Commissioning Policy

Clinical commissioning policy - Questions

Do you support the draft policy statement?

In part

If you selected 'In part', please explain why.:
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 homone 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?

What further changes, if any do you think need to be made to this document?:
The Epidemiology section 4 doesn't mention non-binary people but it should. It 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/

Section 4 uses the term "pre-certificated" twice. This is a throwback to the interim protocol and not used in the current document. They should be removed.

Section 7 (Access to a Specialised Gender identity Clinic) - 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.

Section 7 ii (Support through a period of living in the gender role that is congruent with the individual's gender identity) – Four concerns:

1) It must be made absolutely clear that patients with an interim or full GRC must be considered to have already completed this period of living in the gender role that is congruent with the individual's gender identity. This is because they have proven to the Gender Recognition Panel that they have done this for at least two years.

2) 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, or change their name to a stereotypically male name. If this type of stereotyping is used as a bar to treatment then it will be subject to legal challenge as it is discriminatory on the basis of sex. 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.

3) There must be no requirement for the individual to have achieved a certain 'quality' of life in their gender role, or for them to have participated in any vocational activity (including voluntary work).

4) A trans person being held in a prison that does not match their gender identity must not be seen as a failure to complete this criteria.

Section 7 iii (and page 37) (Provision of recommendations for endocrine and other pharmacological interventions to relieve gender dysphoria and facilitate changes in sex- specific characteristics) - 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 7 v (Provision of interventions to reduce facial hair growth) – This section states that it is only for trans women, however this should also be provided where necessary for non-binary people. This includes non-binary people whose facial hair is caused by testosterone injections.

Section 7 v (Provision of interventions to reduce facial hair growth) – 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 7 vii (Provision of virilising (bilateral partial mastectomy and male chest reconstruction, female-to-male chest surgery) chest surgery) – This should be reworded to make it clear that it is also available to non-binary people.

Section 7 viii (Provision of feminising or virilising genital reconstruction surgery) - 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 7 xiii a (Feminising chest surgery (breast augmentation; augmentation mammoplasty)) - This should be reworded to make it clear that it is also available to non-binary people. Also it 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)"

Page 37 - There is no justification for forbidding facial feminising and masculinising surgery, which is an absolutely essential and clinicially 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 10 (Mechanism for funding) - This 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.

Section 11 (Audit requirements) – The data collected here should be publicly available. Also, it is highly important that the data includes information on patient gender! This should be a breakdown of how many trans men, how many trans women and how many non-binary people are in the system. This will not be known at time of referral so should be collected after initial assessment.

Appendix 1 - There needs to be more consistency about how patients are assessed. For example Charing Cross and Northampton will consider prescribing homone 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 flowchart spell out in greater detail what the assessment process should look like.

We do not think the documents take enough account of the fact that total laparoscopic hysterectomy with salpingo-oopherectomy 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?

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

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 vunerable patient in an incredibly dangerous situation, breaches the UKGPG and could be considered negligence.

We strongly believe that the commissioning policy 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:

Please provide final comments below::
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.