

Response ID ANON-5H8E-S3JS-W

Submitted to Interim Clinical Policy: Puberty suppressing hormones for children and adolescents who have gender incongruence/dysphoria
Submitted on 2023-10-23 09:44:24

About you

1 In what capacity are you responding?

Other

If you have selected 'Other', please specify:
Trans Advocacy Organisation

2 Are you responding on behalf of an organisation?

Yes

If you have selected "Yes", which organisation are you responding on behalf of?:
TransActual

Interim clinical policy

3 Has all the relevant evidence been taken into account?

No

If you selected 'No', please give details::

Because it would be unethical to conduct a RCT on puberty blockers for trans young people and because it has ruled out evidence from studies that do not focus on trans young people or that do not use trans young people as the comparator, the GRADE framework demands a standard of evidence that is not ethical and is not possible.

There has been no consideration of the impact of not accessing puberty suppression. There is a growing body of research that indicates the positive mental health and social outcomes for trans young people accessing puberty suppression. Much of this appears to have been discounted.

There is no reference to evidence on the impact in adult-life of failure to access puberty suppression - for example, the impact on a trans woman of having a permanently deepened voice or the impact of chest binding and double mastectomy on a transmasculine person who experiences dysphoria about their chest.

Furthermore, the differential diagnoses of 'early onset' and 'late onset' have been introduced, despite them not being mentioned anywhere in the research or within WPATH's standards of care. NHS England have stated that they do not yet have definitions for these two diagnoses.

The approach being taken in respect to this policy is contradictory: On one hand, the existing research is not 'good enough' and on the other hand, it's permissible to introduce a differential diagnosis on the basis of no evidence base at all.

The stakeholder engagement report states that " NHS England does not commission based upon guidelines or treatment protocols eg WPATH 8.0 or practices in other countries." It completely fails to acknowledge that the WPATH standards of care are evidence based and peer reviewed and fails to explain why NHSE would not follow international best practice.

4 Does the equality and health inequalities impact assessment reflect the potential impact that might arise as a result of the proposed changes?

No

If you selected 'No', please give details::

Because NHSE have not published the research selection-criteria or offered definitions for 'late onset' and 'early onset', it is not possible to properly assess the accuracy of the EHIA.

If 'late onset' and 'early onset' are determined, for example, by the age at which a trans young person first tells someone that they're trans then the following factors would need to be considered:

- Religion or belief - young people from a religious background might be more concerned about family and community rejection if they come out as trans, if the family holds particular religious beliefs they might also be less likely to have access to information that would help them realise that they're trans (ie they might not know that trans people exist if they haven't seen trans people on TV, in books or in the school curriculum) and may thus take longer to come out. Furthermore, the National LGBT Survey (2018) found that 44% of trans Muslim respondents have had or been offered conversion therapy.
- Sex assigned at birth - it is possible that trans girls or non-binary people assigned male at birth may delay coming out as trans. It is well documented that trans women and people seen as 'feminine men' experience high levels of harassment and discrimination.

- Race - research (for example Growing Up LGBT, Just Like Us, 2021) shows that Black LGBTQ+ young people are more likely to experience feelings of isolation at home and at school. Black people and People of Colour are more likely to have had or been offered conversion therapy - according to the National LGBT Survey (2018), 28% of Black/African/Caribbean/Black British trans respondents, 27% of trans respondents belonging to an 'Other' ethnic group, 27% of Asian/Asian British respondents and 20% of trans respondents from Mixed/Multiple ethnic groups. Race therefore is likely to have an impact on the age at which someone comes out as trans.

TransActual would like to seek reassurance that an individual's disability or neurodivergence will not result in them being excluded from the research.

We believe NHSE to be wrong in the assessment that not all young people accessing the service would be impacted by the protected characteristic of 'gender reassignment'. An individual is protected from discrimination if they have expressed the intention to transition, are transitioning or have transitioned - this includes social transition. This will include most young people accessing the service - not least because the waiting list is several years long, and most of those who are not trans will realise it before being seen by the service. People who are perceived to be trans are also protected from discrimination on the basis of gender reassignment. For the small minority of young people who aren't trans and access the service, it is unlikely that they will not be perceived as trans by others that know they are attending the service.

The language used in the EHIA in relation to sex is inconsistent and unclear. The use of 'natal males' to refer to people assigned male at birth and 'natal females' to refer to people assigned female at birth is inappropriate. We do not know (nor do we need to) what causes someone to be trans or if trans people are 'born this way' - because we don't know this, it is inappropriate to refer to a trans girl as a 'natal male'.

It is important also to acknowledge that the EHIA continues to give undue credence to the suggestion that many trans boys or that being trans is caused by 'internalised homophobia, exposure to social media, trauma, bullying, difficulties in navigating bodily changes at puberty, experiencing sexual objectification, familial and social situations and social contagion'. This is akin to NHSE giving credence to the myths perpetrated by the anti-vax movement when setting policy on childhood vaccinations, or the Royal Astronomical Society giving credence to 'evidence' supplied by the Flat Earth Society.

In relation to Looked After Children and People or Families on a Low Income, the EHIA has failed to consider the disproportionate impact of not being eligible for the research study. Young people with affluent and supportive parents will be able to access puberty suppression privately if they are ineligible for the study, Looked After Children or young people from low income families will not have that option. Therefore, Looked After Children and young people from low income families will be disproportionately impacted.

The EHIA states that 'Other forms of specialist clinical support will remain available through the NHS for this patient cohort', however there is only one form of clinical support which will pause the effects of puberty and access to that will be restricted to participants on the research trial.

5 Are there any changes or additions you think need to be made to this policy?

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We are supportive of research into trans people's health, but only when it is conducted ethically and participation is optional. Making access to puberty suppression contingent on participation in a research trial is unethical. There is plenty of evidence to show the positive impact that puberty suppression can have on trans young people, but NHSE has discounted it. There has been no consideration of the impact of not accessing puberty suppression - either in the immediate term or in adult life (for example, the impact of one's voice having deepened, jawline developed or breasts developed).

TransActual's grave concerns about this approach are compounded by NHSE's manufacture of the differential diagnosis of 'early onset' and 'late onset' dysphoria. Within the documentation about this proposed policy, NHSE state that there is not enough evidence to offer the medication without further research and yet simultaneously introduce a differential diagnosis that they admit to not being able to define and which is completely unevidenced. It is important to recognise too that, given that the means of identifying 'onset' will be to ask the young person, there will be young people who lie in order to be part of the trial. This will render the differential diagnosis pointless because the data will not be accurate.

TransActual urge NHSE to revisit this policy to ensure that:

1. Trans young people are able to access puberty suppression from Tanner Stage 2 if they would like to and if they are able to make an informed decision to consent.
2. Research into the use and impact of puberty suppression builds on the existing evidence base and does not seek to invent new diagnostic criteria where diagnostic criteria already exist.
3. Participation in all research is optional and access to treatment will not be impacted by a decision to participate or not.