

**Response from: Royal College of
Paediatrics and Child Health**

**To: NHS England Consultation on Service
for Children and Young People with Gender
Incongruence: Referral Pathway**

Due: 20th March 2024



About the RCPCH

The **Royal College of Paediatrics and Child Health (RCPCH)** is responsible for training and examining paediatricians, setting professional standards and informing research and policy. RCPCH ('the College') has over 22,000 members in the UK and internationally. We work to transform child health through knowledge, research and expertise, to improve the health and wellbeing of infants, children and young people across the world.

This document sets out RCPCH's response to NHS England's Consultation on proposed [referral pathway for Children and Young People with Gender Incongruence](#). The consultation sets out specific questions to which the RCPCH has responded below and via the online survey platform.

Consultation Questions

The consultation asks respondents to indicate the extent to which they agree with the following statements. There is an opportunity to provide written comments, which are included below.

a) Referrals to the waiting list may only be made by general paediatric services or CYP mental health services.

Agree

We understand there are large waiting lists for children who are gender questioning and it is important that all children receive timely access to care and support. We agree there is a role for general paediatrics and CAMHS to play in supporting these children with their holistic health and wellbeing needs, particularly in the context of current waiting lists for specialist gender services. It is uncommon in other areas of medicine for a referral to be made from primary care to a tertiary service, and aligning this referral pathway with other clinical pathways for children is appropriate.

b) Children under 7 years of age will not be added to the waiting list.

Disagree

We have received advice from the British Society for Paediatric Endocrinology and Diabetes to support us with a view on this recommendation. We are unclear of the rationale behind choosing this age and the service specification would do well to better describe its rationale - for example, if it is commissioning services to respond to the beginning stages of puberty only. Given the context of this service and the implications puberty has to CYP's gender related distress, it may be that NHS England need to consider a model that does not have a lower age limit. If NHS England do intend to bring in a lower age limit to this service, it would be important to provide more information on what the care pathway would be for CYP under 7 years old who may present with distress in relation to their gender identity.

It is unclear where the evidence is to point to CYP under 7 years old not having the intellectual capacity to understand gender identity and or incongruence - there is a divergence of views about this from RCPCH members and more work is needed to underpin this statement with evidence.

It would be helpful for NHS England to better explain this policy proposal and ensure it does not trespass upon the age discrimination provisions within the Equality Act 2010. Within the Equality and Health Inequalities Impact Assessment (EHIA) a statement is made that seeks to justify this approach within a safeguarding context. It is unclear what is meant by 'safeguarding context' and more clarity is needed to ensure correct interpretation is made resulting in an appropriate clinical response.

c) Young people aged 17 years will not be added to the waiting list of the children and young people's gender incongruence service as a temporary measure in response to long waiting times.

Neither agree nor disagree

The service specification needs to be clearer as to what the referral pathway for this group of young people will be. Young people aged 17 have the same right to healthcare access as their younger and older peers, and the current proposals which require the extra step of the young person being required to consult their GP in order to access the adult waiting list presents a disparity in access to gender services.

We understand that the length of the waiting list for CYP Gender Identity services currently means that 17-year-olds are unlikely to access care before they turn 18, however we suggest that the pre-referral consultation service is afforded the function to refer directly onto the adult waiting list to prevent 17 year olds from having to face an extra barrier to referral.

d) Young people who reach 17 years of age while on the waiting list for the children and young people's gender incongruence service will be removed from the waiting list; they may seek a referral into the adult gender service with their original referral date into the CYP service honoured.

Disagree

While we support that the original referral date into the CYP service will be honoured on the adult waiting list, we are concerned that the proposal in its current form will negatively impact those most vulnerable by requiring the patient to contact their GP for a new referral, as opposed to being transferred directly onto the adult equivalent waiting list for the specialist service, as they would in other areas of healthcare provision. This is outside of standard practice for the transition from CYP to adult healthcare services and may be at risk of trespassing upon the age discrimination provisions within the Equality Act 2010.

For most specialist services, children who 'age out' while on the waiting list will either continue to be seen by paediatric services or automatically transferred to the adult waiting list of the equivalent specialist service without the need for GP intervention. The RCPCH suggests that this practice is upheld for gender identity services.

e) The role of the pre-referral consultation service.

Somewhat disagree

Consideration should be given to ensure that the outcomes/objectives set for the National Referral Support Service (NRSS) relating to reducing the waiting list do not compromise the quality of care provided to children and young people.

Paediatricians and mental health practitioners referring into the service will require training and resource to understand the requirements of the referral form in order to ensure that their referrals are accepted promptly by the NRSS when it is their professional opinion that the child or young person requires intervention by Gender Identity Services. Additionally, training will be required to support paediatricians in managing the potential gender related distress in this patient group, to ensure that they are confident in providing high quality, safe and effective care to these patients while they are facing long waiting times to be seen by Gender Identify Services.

Any decisions made to change the referral status of children and young people on the existing waiting list must be made with the consent of that child and their parent/carers, and the rationale for this fully explored and explained. The RCPCH's view is that such changes should be reviewed by a clinician prior to a final decision being made. No child on the waiting list should be removed without a clinical review of their gender related distress and a risk assessment completed and more signposting to support for the CYP and their family.

The RCPCH welcomes the opportunities afforded by the NRSS to identify interim or additional support needs of children and young people on the waiting list. It is essential that a clear process for referral to the correct service for identified additional needs is in place in order to ensure that children and young people are appropriately referred in a timely way and that the expectations on paediatricians are clear.

f) Any other element of the service specification.

Neither agree nor disagree

Whilst the role of primary care in the treatment of CYP with gender dysphoria/incongruence is set to change, it would be helpful to understand from NHS England whether primary care will play a role in future shared care arrangements as some CYP from remote and rural regions may not easily be able to access one of the two specialist service hubs.

Further clarification is also required as to the linkage between CYP mental health services and paediatric services with regard to referral, the process for joint referral and establishing responsibility for care arrangements while on the waiting list. Consideration must be given to data sharing and interoperability within and between these services.

4. To what extent do you agree that the Equality and Health Inequalities Impact Assessment reflects the potential impact on health inequalities which might arise as a result of the proposed changes?

Disagree

More clarity is needed on the views around the safeguarding context of CYP under 7 years old in context of their gender questioning and potential onward referral to the service. Additionally, clarity around provisions for 17 year olds and their access to the relevant adult services needs to be provided before a full assessment can be made against the potential for health inequalities to arise or be widened.