August 2023

New referral pathway for children & young people's gender incongruence service: stakeholder consultation for NHS England – Mermaids' Response

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

Strongly opposed

Comments (180 words)

- Removing the GPs, the most common, accessible route (65% of current referrals), is given no justification. Given that GPs will still usually need to be part of the referral pathway (to refer to paediatrics or CYPMHS), this specification appears to solely be making referrals more difficult.
- CYPMHS and paediatric services have long waiting lists. Why are you introducing further distressing delays to accessing the gender service?
- The proposed pathway requires a child or young person (CYP) to interface with multiple gatekeepers who lack gender-specific training, yet must determine if there is a 'potential presentation of gender incongruence' to refer onward. This increases the sites of potential exclusion by untrained or prejudiced clinicians, and requires the patient to 'prove themselves' continuously.
- Removal of non-health professionals (e.g. social workers) affects the most marginalised in our community, especially those already in close contact with social workers, those with unsupportive families or GPs, and demographics with historically lower rates of NHS engagement. Patients should be able to refer via one trusted adult, e.g. social workers, teachers.

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

Disagree

Comments (180 words)

- Given the 4+ year waiting period, there is no justification for limiting a referral to those aged over 7.
- The EHIA's justification for the lower limit of 7 years is that they 'may not be expected to have sufficiently developed their intellectual understanding of…sex and gender' (a claim that must be justified with evidence in its next publication). On the basis of this reasoning, however, the limitation should be

based on the age of their first appointment, not point of referral. Otherwise, this is delaying a child's already long waiting period further, and (at current waiting times) effectively means that no one under age 11 will be seen by the gender service.

Young people aged 17 years will not be added to the waiting list of the children and young people's gender incongruence service

Agree

Comments (180 words)

- Given current waiting times, this is a reasonable decision.
- However, the process by which young people are transferred into the adult service waiting list needs to be as seamless and simple as possible, and not present even further steps/barriers to inclusion on the adult waiting list.

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 that waiting list; and they may join the waiting list of an adult gender service with their original referral date honoured

Partially agree

Comments (180 words)

- This is a sensible approach, in cases where the young person will not be seen by the CYP service within their 17th year. However, if they are a number of months away from a first appointment, it would be irresponsible for them to be transferred into a longer waiting list.
- However, it is concerning that the patient must have their original referrer actively refer them into the adult service - rather than automatic. There is a high likelihood, due to poor communication, change in location, or the referrer no longer being in post, that the young person will not be efficiently transferred to the adult waiting list. We recommend that the transfer be automatically managed through NRSS, and this be communicated to the young person with an opt-out option provided.

Role of the pre-referral consultation service

Partially disagree

Comments (180 words)

- This consultation service could be useful in providing informed, interim support to the CYP while on the waiting list.
- However, the specification must remove the potential outcome of being removed from the waiting list (i.e. that the CYP 'does not meet the access criteria'). The CYP will have already engaged with at least two services (GP and paediatrics/CYPMHS), so a third gatekeeping process seems wholly disproportionate. Importantly, the absence of the CYP or parents/guardians will make any such decision to block a referral opaque, non-collaborative and removes the voice of the CYP. We therefore recommend that the potential outcome of rejection from the waiting list be removed.
- Separately, given this meeting will decide the local care plan for the CYP, we strongly recommend that the parent/guardian and CYP are directly consulted and involved.

Is there any other element of the service specification you wish to comment on?

- The appeals process at each stage must be clearer. There needs to be a route for CYP and their families to appeal decisions made by any gatekeeper in the process, and/or ask for a second opinion. This is especially important given the lack of routine training in both primary and secondary services to understand gender incongruence, and this specification enables various single points of failure.
- What is the route for CYP with unsupportive and/or abusive families? The Arden & GEM website states that referrals won't be accepted by under 16s without parental consent.
- It is unclear who 'holds' the CYP after they have been referred to CYP gender services. The specification infers CYPMHS or paediatric services would retain clinical responsibility while they are on the waiting list, but is this practical or likely given their own waiting lists and overburdened caseloads? This is especially important given these referrers will be expected to re-refer 17+ year olds into adult services.
- What is the bar for 'mental health needs' requiring referral in the CYPMHS versus paediatric services, given most trans youth will experience some form of mental distress while waiting 4+ years for access to gender services?
- In the section on NRSS vetting of referrals, the specification states that this vetting process might also result in a recommendation that the referral not be accepted. Given NRSS do not have clinical expertise, what would the justification be for this? How would this be communicated to patients? This should only be in the case of being referred onto adult services, and this be made explicit.
- It is useful that patients will be given the choice of which Hub to attend.

- Appendix B, summarising the pathway, would be very useful to include for the public consultation to make this clearer and easier to understand.

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

Comments (180 words)

- Minimum age threshold: given the 5 year waitlist, the justification given for this does not hold - the patient would not be seen at age 7, but many years after referral, e.g. 11 years.
- Maximum age threshold/process: By adding an extra step of re-referral, rather than automatic/opt-out referral into adult service, there's a high risk of poor communication channels leading to referrals falling through the cracks.
- Gender reassignment: The EHIA notes the issues of unsupportive or uninformed GPs blocking care, yet the specification still requires GPs as the first step in the pathway in most cases. With no alternative routes or appeal processes, the single point of failure will prevent access.
- Disability: while noting concerns of neuroableism, the EHIA and specification fail to allay these concerns. They must state that waiting times and service access will not be different for neurodiverse CYP, and embed measurements to ensure this.
- Race and ethnicity: the EHIA notes that BAME populations are less likely to access mental health services. Reducing the referral routes to either mental health services or paediatricians exacerbates this.

Do you have any further comments on the proposal? If so, please submit these in under 500 words.

It is clear from consultation conversations with our service users, both parents and CYP, that the removal of GPs and non-clinical professions from the referral pathway is highly distressing and unjustified. Given the current poor medical training on gender-related healthcare, and therefore the high likelihood for CYP to encounter barriers to referrals on the basis of ignorance or prejudice, it is necessary for a multiplicity of referral points to be available. Our service users reflect that this specification appears to reduce options, add barriers and gatekeepers, and aim to reduce the waiting list by preventing CYP from joining it.