

BMA response to the NHS consultation on the referral pathway into the Children and Young People's Gender Incongruence Service (March 2024)

About the BMA

The BMA (British Medical Association) is a professional association and trade union representing and negotiating on behalf of all doctors and medical students in the UK. It is a leading voice advocating for outstanding health care and a healthy population. It is an association providing members with excellent individual services and support throughout their lives.

While we represent members with a diverse range of views in this area, the BMA's policy is that we 'affirm the rights of transgender and nonbinary individuals to access healthcare and live their lives with dignity, including having their identity respected'. This includes ensuring that under-18s can access healthcare in line with existing principles of consent established by UK Case Law and guidelines published by the public bodies which set the standards for healthcare.

We welcome efforts to ensure that healthcare services for children and young people are fit for purpose and readily accessible. Providing a high-quality standard of care to patients in a timely fashion should be the overarching goal of this service. However, we are concerned that some of the proposals set out in the consultation may increase barriers to accessing much needed support.

Summary

The BMA is concerned by the proposed referral pathway into the Children and Young People's Gender Incongruence Service. This proposal attempts to respond to increased demand for specialist care by narrowing access to services, rather than by increasing provision. We are concerned that the proposals will exacerbate pressures on primary care, secondary care, and adult gender services, with resultant detrimental impacts on patient health and wellbeing.

We are particularly concerned about the lack of clarity around care pathways for teenagers and about the role of parents/guardians. It is imperative that all children and young people can access healthcare in line with existing principles of consent established by UK Case Law, i.e. Gillick competence. This is of utmost importance given that not all young people's families support them to seek care for gender incongruence.

We support the proposals that:

- 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 (as per proposal C). However, we seek clarification on when this temporary measure will be lifted.
- 2. Secondary care providers are offered resources to support their work with children and young people with gender incongruence (as per proposal E).

We further recommend that:

- 3. The requirement for GPs to refer to CYPMHS (Children and Young People's Mental Health Services)/ paediatric care is removed.
- 4. The referral pathway allows GPs to refer to CYPMHS / paediatric care and CYPGIS (Children and Young People Gender Identity Service) concurrently.
- 5. Restrictions on who can refer to the CYPGIS are eased.



- 6. Healthcare providers in general practice, CYPMHS, and paediatric services who work with any patient with gender incongruence are offered fully funded training to equip them with the knowledge to make a referral to the waiting list for CYPGIS.
- 7. Before implementing a minimum age threshold for the CYPGIS, the NHS carries out an assessment to identify a clinically meaningful age threshold. Any clinically meaningful minimum age threshold should relate to age at first review by the CYPGIS rather than their age at referral.
- 8. Young people who reach 17 years of age while on the waiting list should be contacted and given the choice to either remain on the waiting list for a further year, be moved to the adult waiting list, or leave the waiting list if circumstances have changed. The CYPGIS should not require that GPs refer on to adult services.
- 9. NHSE commissions work to map demand for the CYPGIS and adult gender identity services and publishes proposals to match provision to demand.
- 10. The requirement for a pre-consultation is removed.
- 11. NHSE commissions gender outreach workers working at a neighbourhood team level.
- 12. An early help meeting is made available to families to discuss patients' potential mental health needs and neurodiversity, as well as their gender incongruence.

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

We are concerned by the proposal to restrict who can refer patients to the CYPGIS. We recognise the concerns of the Care Quality Commission¹ and Dr Hillary Cass² about the lack of support or risk assessment around children and young people while they remained on the waiting list for the Tavistock GIDS (Gender Identity Development Service). Many children who present to gender incongruence services have additional complex needs that should be considered holistically, such as mental health needs or neurodivergence. However, we do not believe that limiting referral sources will resolve this issue. This is due to the conflation of needs in this approach, the lack of capacity across secondary care services for children and young people, the complexity of the patient journey proposed, and the lack of specialist expertise among healthcare professionals in general practice, general paediatric services, and CYPMHS.

Conflation of gender diversity and mental health/neurodivergence

The majority of gender diverse people do not exhibit complexity over and above their gender related needs. Requiring that children and young people are first assessed for conditions unrelated to their gender incongruence implies that the root cause of gender incongruence is often mental health needs or neurodivergence.

Patients who do have coexisting mental health needs or neurodivergence should be offered parallel assessments for these needs and for their gender incongruence. This is particularly important given that mental health conditions such as anxiety and depression may be a consequence of gender incongruence, with mental health often improving when patients have timely access to care.³

¹ <u>Care Quality Commission demands improved waiting times at Tavistock and Portman NHS Foundation Trust</u>. Care Quality Commission, 2021.

² <u>Independent review of gender identity services for children and young people: Interim report</u>. The Cass Review, 2022.

³ <u>Support for parents/carers of primary school aged gender diverse children in England, UK: a mixed-method</u> <u>analysis of experiences with health services</u>. Rickett, Johnson, Ingle, & Reynolds, 2020.



Waiting lists and lack of capacity

The practical impact of requiring patients to be referred through secondary care would create bottlenecks and backlogs in an already chronically overstretched system, particularly in CYPMHS. Without significant investment, neither general paediatric services nor CYPMHS have the capacity to take on the additional workload proposed in this consultation.

As of 2023, the waiting list for general paediatrics was 416,790, with more than 21,000 children waiting over a year for treatment.⁴ The wait for CYPMHS was an average of 21 weeks to first appointment in England, with an average longest wait of 93 weeks.⁵ Some of our members report that in parts of the country, only patients with acute psychosis will be accepted for specialist mental health support in secondary care. Streamlining care will not make up for the chronic lack of capacity in these services and will only serve to worsen waiting times, both for children and young people with gender incongruence and for the general patient population.

As of 2021, the waiting time for a first appointment at GIDS was over two years.² If these waiting times persist, a referral pathway that relies on a secondary referral to commence on the CYPGIS waiting list could result in a patient waiting several years before commencing treatment for gender incongruence. These delays may have adverse psychological and emotional implications for children and their families, particularly considering the importance of timely interventions for gender incongruence.⁶

Lack of training in primary and secondary care

The Cass Review Interim Report² and NHS consultation documents stress the importance of holistic care for gender incongruence. A comprehensive understanding of a child's physical, mental, and social well-being is crucial for providing effective and individualised care for gender incongruence. However, we are concerned that healthcare providers in general practice, CYPMHS, and paediatric care do not have expertise in gender incongruence, and will thus be limited in their ability to conduct holistic assessments of patients' needs. In contrast, gender specialist healthcare providers are often drawn from backgrounds in paediatric services and CYPMHS and do have the capability to undertake holistic assessments.

The consultation documents are clear that GPs are expected to have "the skills to identify a potential presentation of gender incongruence [...] to identify co-existing other health needs, and to determine whether the degree of distress merits referral". However, there are no specifications given for how GPs will be supported to do this. While the consultation documents stipulate that resources will be available for secondary care providers in CYPMHS and general paediatrics conducting pre-referral consultations, no comprehensive training is offered.

Some of our members in primary and secondary care have consistently raised concerns that an expectation to provide certain types of care and treatment for transgender patients falls outside their competency. A new care pathway that increases their role would only therefore work effectively to streamline care where doctors have a competent and nuanced understanding of the ways in which mental health and neurological needs interact with gender incongruence.

⁴ *More than 20,000 children waiting over a year for treatment*. RCPCH, 2023.

⁵ <u>Revealed: the postcode lottery in child and adolescent mental health care</u>. Smith, 2023.

⁶ <u>Thinking Time, Shifting Goalposts and Ticking Time Bombs: Experiences of Waiting on the Gender Identity</u> <u>Development Service Waiting List</u>. McKay, Kennedy, Wright, & Young, 2022.



Fragmentation and complexity

The proposed referral pathway may increase the risk of disengagement in the delivery of care. We fear that the extensive waiting times and requirements for patients to be seen by multiple healthcare providers with no specialist knowledge of gender incongruence may lead patients to disengage with the system entirely and to seek care from unregulated providers, with potentially adverse psychological and emotional consequences.

We are also concerned that the requirement for multiple assessments may inadvertently result in reduced access to healthcare, where healthcare providers act as gatekeepers to specialist services. This may result in some children, particularly those with co-existing autism and/or mental health conditions, facing unnecessary barriers to accessing the care they need.

Alternative proposals for referral

To resolve the issues outlined above, we make the following recommendations:

- The requirement for GPs to refer to CYPMHS/paediatric care is removed.
- The referral pathway allows GPs to refer to CYPMHS/paediatric care and CYPGIS concurrently.
- Restrictions on who can refer to the CYPGIS are eased.
- Healthcare providers in general practice, CYMHS, and paediatric services who work with any children with gender incongruence should be offered fully funded training to equip them with the knowledge to make a referral to the waiting list for CYPGIS.

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

There is currently no minimum age threshold for referrals to the children and young people's gender incongruence service. The consultation documents state that "there is no firm clinical evidence to determine whether a minimum age threshold should apply for referrals into the service and, if so, what that age threshold should be".

The Equality and Health Inequalities Impact Assessment for this consultation states that a minimum age threshold of 7 years for referral into the service is being proposed as by this time children may have more developed their cognitive, comprehension and communication skills to an extent that they will be able to engage with health professionals in the process of a holistic clinical assessment and formulation.

We are concerned that the decision to set a minimum age threshold at age 7 is based on assumptions of cognitive ability, rather than firm clinical evidence. Paediatric experts propose that gender identity can be fully developed by 2-3 years of age.⁷ Research on children who transitioned in early childhood indicates that rates of retransition are low.⁸ We therefore recommend that before implementing a minimum age threshold, NHSE carries out an assessment to identify a clinically meaningful age threshold.

Furthermore, due to waiting lists for specialist services, there is often a significant gap between a child's age at the time of referral and their age at commencement of treatment. As of 2021, the waiting time for a first appointment at GIDS was over two years.² These excessive waiting times could result in children waiting many years beyond age 7 before accessing treatment. We therefore recommend that any clinically meaningful age threshold should relate to age at first review by the new CYPGIS rather than their age at referral.

⁷ <u>Nelson book of paediatrics</u>. Kliegman & St Geme III, 2019.

⁸ <u>Gender identity 5 years after social transition</u>. Olson et al, 2022.



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.

The consultation documents are clear that the maximum referral age of 16 is being proposed as a temporary measure and will be revised back to 18 once waiting times for the children's service have reduced sufficiently.

In recognition of the unlikelihood that young people aged 17 will not be assessed before they turn 18, we support this proposal as a temporary measure. We seek clarification on when this temporary measure will be lifted.

Furthermore, we would welcome confirmation that referrals of 17-year-olds will follow the adult referral pathway and that referrers and patients will be made aware of this route.

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.

We seek clarification on whether upper age limits for the waiting list are a temporary or a permanent measure. The proposal for adding young people to the waiting list (see above) sets out that an upper age limit of 18 will be implemented once waiting times have been reduced. However, the proposal for removing young people from the waiting list sets out that they will be removed at 17.

Young people who reach 17 years of age while on the waiting list for the CYPGIS should not be automatically removed from the waiting list. Waiting times for adult services remain very long due to significant workforce capacity constraints.

To ensure continuity of care, young people should not be required to seek a GP referral into the adult gender identity service. Discharging patients from the waiting list to the GP and requiring a new referral creates an additional obstacle to care and additional work for GPs. We consider this measure to be an attempt to artificially cut down the waiting list, with no benefit to patient care.

We recommend that young people who reach 17 years of age while on the waiting list are contacted and given the option to a) remain on the waiting list for children and young people's services for a further year, b) be added to the waiting list for the adult gender identity services, or c) be removed from all waiting lists. If the young person decides to be added to the waiting list for adult gender identity services, their initial referral date should be honoured.

In addition to these changes, we recommend that NHSE commissions work to map demand for CYPGIS and publishes proposals to match provision to demand for both CYPGIS and adult services. Given that waiting times for adult services remain very long, simply moving patients from one waiting list to another is not a sustainable solution. While we recommend that young people who are moved from the CYPGIS waiting list to the adult waiting list have their initial referral date honoured, we are aware that this may extend waiting times for patients who join the waiting list as adults. We would therefore welcome dialogue between NHSE, CYGIS, and adult gender identity services to remedy this issue for the long term.

e) The role of the pre-referral consultation service

We welcome the proposal to provide resources and support to healthcare providers in CYPMHS and paediatric services. However, we are concerned that the new requirement for a pre-referral consultation may cause further delays and barriers to access for children and young people. The care



pathway proposed in this referral pathway will require patients to attend their general practitioner, wait for months to years for assessment with CYMHS and/or paediatric services, wait again for the result of a pre-referral consultation, and then wait further months or years on a waiting list for specialist care, all before they are seen by a healthcare provider with specialist knowledge of gender identity.

Research has indicated that patients and their families can experience feeling distressed and stuck while on waiting lists for gender identity services. In a qualitative study of families' experience on the waiting list for the Tavistock GIDS, parents felt that they should have received more practical information to support their children.⁶ They proposed that the GIDS could offer regular check-ins for families on the waiting list to provide reassurance and advice.

We believe that the requirement for a pre-referral consultation is an inefficient use of resources. This process will increase the workload of the CYPGIS, with very little benefit to patients or families who require direct support. Families would be more likely to benefit from practical support at an earlier stage in the process.

We recommend that:

- The requirement for a pre-consultation is removed. While local secondary care providers should have the option to liaise with specialists, this should not be an obligatory step in the referral pathway.
- NHSE commissions outreach workers working at a neighbourhood team level to specialise in gender identity. This service could be modelled on existing services for <u>adult gender identity</u> <u>services</u> and <u>memory assessment services</u>. A gender outreach worker could act as a point of contact for patients and their families, support you throughout the process of assessment, and act as a liaison between schools, primary care, secondary care, and the CYPGIS. This individual could also provide regular check-ins for patients on the waiting list for the CYPGIS.
- To ensure holistic care and that the patient's gender incongruence is the focus, an <u>early help</u> meeting should be available to families. This meeting could be used to discuss the potential mental health needs and neurodiversity, as well as their gender incongruence. The meeting would be attended by the support worker and any other relevant educational or health professionals.

f) Any other element of the service specification

We are concerned that patients who do not meet the criteria for the CYPGIS will be denied support from healthcare providers with specialist knowledge, and instead be placed on a local care plan that may not address their gender incongruence. We would therefore welcome further clarification on how children and young people on local care plans will be supported.

We would also welcome further clarification on the ways in which the Gender Experience Survey (GES) will be used to assess patients. Some of our members have raised concerns that the GES could be used to gatekeep patients from accessing specialist care. Furthermore, the statement "to support the initial discussion with primary care young people aged 16 years and over, and the parents/carers of children under 16 years, are encouraged to complete a national standardised Gender Experience Summary" is not consistent with Gillick competence. Children under 16 should be afforded the opportunity to make their own submission independent of their parents/guardians if they are Gillick competent. This is of utmost importance given that not all young people's families support them to seek care for gender incongruence.



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?

The Equality and Health Inequalities Impact Assessment attempts a comprehensive overview of the potential impact on health inequalities which may arise as a result of the proposed changes. It does not, however, adequately acknowledge that there may be unfavourable outcomes for some individuals as a result of the proposed changes:

- Pg5 We seek evidence to substantiate the claim that "the absence of a minimum age threshold could result in unnecessary and inappropriate referrals being made". If there is evidence that GPs have made referrals on the basis of opposite-sex behaviours rather than gender incongruence (as implied in the EHIA), it may be more appropriate to provide training resources to GPs than to implement a minimum age threshold arbitrarily.
- Pg8 The document states that the proposal does not discriminate against individuals who may share the protected characteristic of age, and that the mitigation for any age-related inequalities is that this approach is temporary. This mitigation should be monitored to assess the potential negative impact on 17-18-year-olds throughout the 2024-25 temporary service period.
- Pg24 The document states that "children under 7 years of age could not be expected to have sufficiently developed their intellectual understanding of, and comprehension of, sex and gender to be able to understand the reasons for, and potential consequences of, a referral to a specialist gender incongruence service". However, no evidence is presented to support this argument. Existing evidence indicates that both cisgender and transgender children can develop their gender identity at a younger age.^{7,8}
- Pg37 The statement that "for young people of 16 and under, consent to treatment should usually be sought from the child and from one or both parents" is incorrect. Children under the age of 16 can consent to their own treatment if they are believed to have enough intelligence, competence, and understanding to fully appreciate what is involved in their treatment, i.e. Gillick competence.⁹ Furthermore, any statement referring to parents should also refer to guardians, families, and carers.
- Pg39 The document states that the proposed referral pathway will improve experiences for patients with poor literacy or poor health literacy. However, we are concerned that the complexity of the new pathway will pose challenges for this group. The requirement for multiple steps and assessments, all of which will be communicated through letter, may be challenging for this group. It is therefore important that the referral pathway is made as simple as possible and that outreach workers are available to all patients (see pg 6 of this response).

⁹ <u>Children and young people: Consent to treatment</u>. NHS UK, 2022.