BMA response to the NHS England consultation on the interim service specification for specialist gender dysphoria services for children and young people (December 2022)

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'. We welcome efforts to ensure that healthcare services for this group of patients 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.

We acknowledge that the interim service specification is intended to be in place for a temporary period, pending the final outcomes of the independent Cass review next year. However, regardless of how long the interim specification is intended to be in place, it is important that any changes to existing services do not adversely affect either patients or the healthcare professionals responsible for their care.

In summary, our key concerns with the proposals are:

- Access to specialist services to support children and young people is already unacceptably poor. We are gravely concerned that these proposals, if enacted, will serve to worsen this situation by creating further barriers to timely access to care for this extremely vulnerable patient group.
- Elements of the proposals present ethical concerns, particularly in relation to the proposals around safeguarding, mandatory participation in research, and the removal of agency and autonomy from children and young people
- There is insufficient capacity and confidence on this complex area of medical care within general practice at this time to render these proposals effective or practical.

<u>Further barriers to patients accessing care in a timely fashion</u>

As the consultation documents make clear, there are already excessive and unacceptable waiting times for children and young people to access specialist care. We are therefore concerned that the service specification outlines an additional stage in the process which is likely to increase these already unacceptable delays; namely, the new requirement for referral to the Service to include a consultation meeting between the Phase 1 service and the relevant local secondary healthcare team *and / or the GP.* The new requirement for a pre-referral consultation may cause more delays and barriers to access, particularly where GPs are unfamiliar with the new process and with gender dysphoria more widely.

Restrictions on who can refer

We are also concerned at the proposal to restrict who can refer people into the Service. The practical impact of trying to put more patients through fewer referral routes would potentially be creating a greater blockage and inevitable backlogs in an already extremely overstretched system, with potential impacts on these wider services, such as CAMHS.

Our members have consistently raised concerns that many of them in the current model of care do not feel competent to provide certain types of care and treatment for patients seeking gender dysphoria related treatment. A new model that increases their role without the necessary training and resources to support this, in both primary and secondary care, would only therefore work effectively to streamline care where doctors have already built up this level of competence and nuanced understanding of the care needs for patients seeking care and treatments under/linked to the gender dysphoria classification.

Requirement of medical diagnosis of gender dysphoria

Requiring a diagnosis of gender dysphoria in order to access the service may pressure some young people into feeling they need to make concrete decisions around their gender identity in order to access services, rather than having necessary space for exploring their identity.

It is unclear why the service specification has been predicated on the narrower diagnostic criteria for gender dysphoria contained in DSM-V rather than the current globally accepted standard and diagnostic criteria for gender incongruence set out by the WHO in ICD-11, of which the UK is a signatory. We echo the concerns set out by WPATH that the proposals would seem to 'triage treatment based on an ability of the child or young person to prove the severity of their gender dysphoria.'[1]

Aside from the troubling ethical implications of requiring children and young people to experience or demonstrate distress in order to access care, we question how this element of the specification would work in practice, including who will be responsible for determining what encompasses 'clinically significant' distress or 'significant impairment in social functioning', and on what evidence any such assessments would be based. This is particularly challenging due to the relative lack of expertise of many GPs and non-specialist healthcare professionals in recognising and managing gender dysphoria in young people. We welcome the recognition in the Cass review response to the draft proposals[2] that additional training to build confidence and capacity among healthcare professionals will be paramount to improving services; however, this will take both time and resources to implement effectively. Furthermore, as DSM-V is not the standard diagnostic criteria used in most UK settings for coding and recording diagnoses, this variation is likely to introduce further confusion and inconsistency into statistical and data management used to facilitate healthcare provision.

Increasing the role of the GP

It is unclear from the information provided what the intended role of the GP, as an expert generalist, would be and in what circumstances they would be required to attend pre-referral meetings;

[1] https://www.wpath.org/media/cms/Documents/Public%20Policies/2022/25.11.22%20AUSPATH%20Statement%20reworked%20for%20WPATH%20Final%20ASIAPATH.EPATH.PATHA.USPATH.pdf?_t=1669428978

[2] https://cass.independent-review.uk/publications/

however, in light of the extreme workload pressures on general practice we are concerned that this would lead to increased delays at the initiation point of the proposed clinical pathway.

Further measures outlined in the consultation which restrict patient options (such as new restrictions on if and how the Service will engage with patients who seek to initiate treatment through private providers) add further potential barriers to children and young people accessing the support they may need in a timely fashion.

Prior to any agreement of this interim specification, we would welcome urgent clarification on what the role of the GP in such meetings would be, what guidance would be given to GPs in order to allow them to discharge their duties in such meetings, and an indication of how this additional work is expected to be absorbed in general practice. If implemented, this proposal must be carefully evaluated before any decision is made to include this in the final service specification, to ensure that it does not add further undue delay to children and young people being placed on the waiting list for specialist treatment.

Safeguarding proposals

We are particularly concerned at the proposal that GPs would be expected to be responsible for automatically 'initiating local safeguarding protocols' in cases where children, young people and/or their families have sourced hormone treatments from unregulated sources. Whilst accessing hormone treatments from an unregulated source may give rise to potential safeguarding issues each case would need to be assessed on the individual circumstances and whether the threshold for potential or actual serious harm was met to justify escalation to social services, rather than as an automatic requirement. A blanket stipulation that accessing regulated private care or treatment through unregulated sources is in itself evidence of a reportable risk of harm is likely to prevent young people and their families from engaging with healthcare services at all.

We query why this particular group of patients and their families appear to be singled out for such a stringent approach, which is likely to lead to increased reluctance to engage with GP services, potentially increasing and entrenching health inequalities and preventing the broader provision of healthcare. This proposal would place doctors in an extremely difficult position with regard to taking a harm reduction approach to the most vulnerable patients, maintaining good doctor-patient relationships and avoiding conflict with distressed patients and their families. Effective therapeutic relationships between doctor and patients are predicated upon trust. We cannot see how the potential threat of a safeguarding referral is conducive to establishing or maintaining this trust and in fact may materially decrease trust in the healthcare profession for these patients and the wider population.

Concerns over potential safeguarding referrals, coupled with the refusal of the Service to accept patients already on GnRHa analogues from unregulated sources, may further reduce opportunities for conversations that might encourage these patients to move to more appropriate treatment pathways. This also seems to contradict the position set out by the GMC, which states that doctors should *"encourage [your] patient to be open about their use of alternative remedies, illegal substances and medicines obtained online or face to face, as well as whether or not they have taken prescribed medicines as directed in the past."* [3]

[3] www.gmc-uk.org/-/media/documents/prescribing-guidance-before-cie_pdf-85470847.pdf

We would suggest that this element of the proposal is removed and that any decisions on initiating safeguarding measures, if deemed necessary in the best interests of the child or young person, remain the decision of the professional who identifies such a concern, on a case-by-case basis,

Social transition

We are concerned that the specification seeks to medicalise social transition and states that social transition should only be considered '*where the approach is necessary for the alleviation of, or prevention of, clinically significant distress or significant impairment in social functioning and the young person is able to fully comprehend the implications of affirming a social transition.*' For many young people, social transition is positive for their mental health and wellbeing. As noted in the Cass review response, at the point of presentation to NHS services, some children and young people will have socially transitioned already, and this decision should rest with the individual young person. With current waiting times, it is unrealistic to expect young people to wait to be seen by a specialist gender service before considering making a social transition.

The proposals reflect a shift away from a person-centred approach in which children and young people have a key role in decision making about their own lives and care. The proposals reflect an unfortunate step back towards an overtly medicalised and medically paternalistic approach, which fails to recognise the highly individual nature of children and young people's experiences or their own developing autonomy in relation to exploring their identity.

Mandatory participation in research

This is a complex area which needs to be thought through carefully, given that there are diverse views on whether this an experimental or established treatment. While we strongly support increased participation in research which helps to inform the evidence base on appropriate care, we are concerned at the proposal that NHS England will *only* commission GnRHa in the context of a formal research protocol, the form of which is not sufficiently set out in the proposals. Unless this is part of a clinical trial, we cannot see a way in which patients could meaningfully give free and informed consent to participation in research as a condition of access to treatment. As such, this element of the proposal potentially stands in contradiction to the long-established ethical principles around informed consent and freely agreed participation set out in the World Medical Association Declaration of Helsinki. [4]

The proposal also appears to conflict with Paragraph 17 of the GMC's Good practice in research, which states:

'You should make sure that participants are not encouraged to volunteer more frequently than is advisable or against their best interests. You should make sure that nobody takes part repeatedly in research projects if it might lead to a risk of significant harm to them. You should make sure that any necessary safeguards are in place to protect anybody who may be vulnerable to pressure to take part in research.'

[4] https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/

This approach also runs the risk of undermining the quality of the research, as patients may feel that access to further treatment may be dependent on how they participate or respond within the research project. It is also not clear at this point what the 'eligibility criteria' will be and how much this requirement will impact on the ability of young people to access clinically appropriate treatment. It may also introduce further delays into the process while the research protocols are agreed and developed.

Evaluation of the impact of changes

As set out above, we believe that changes are needed to ensure the specification is fit for purpose. We would welcome clarification on how the impact of a suitably revised service specification, once developed, will be monitored and evaluated, and how both healthcare professionals and, crucially, patients and their families, will be engaged in the development of the final specification.

We hope this response has been helpful and would be happy to discuss our concerns further with you as needed.