

John Stewart National Director Specialised Commissioning NHS England

To: Chief Executives Chief Medical Officers of NHS Trusts providing Adult Gender Dysphoria Clinics

Professor James Palmer Medical Director Specialised Commissioning NHS England

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Review of NHS Adult Gender Dysphoria Clinics

We are writing to you as the Chief Executives and Chief Medical Officers of the organisations that provide Adult Gender Dysphoria Clinics (GDC) in England. The purpose of this letter is threefold:

- to draw your attention to the publication of the <u>final report</u> tomorrow (10 April, 2024) of the independent review of children and young people's gender services led by Dr Hilary Cass which includes findings and recommendations that are relevant to the adult services;
- to inform you that NHS England will be launching a review into the operation and delivery of the adult GDCs, alongside the existing planned review of the adult gender dysphoria service specification; and
- to set out some immediate next steps that will require your support and cooperation if we are all to effectively drive forward improvements we want to see.

Cass Review Final Report

The final report of the independent review of gender services for children and young people (the Cass Review) will be published on 10 April 2024. Although the review was focused on services for young people below the age of 18 years, the terms of reference included the relationship between the paediatric service and adult services given that transfers of care can be made to adult services from 17 years of age.

Furthermore, the review team also had an understandable interest in how care is delivered for young people between the age of 17 and 25 years of age. The final report makes a number of observations that are relevant to adult services, including, but not limited to:

- concerns put to the review team by current and former staff working in the adult gender clinics about clinical practice, particularly in regard to individuals with complex co-presentations and undiagnosed conditions;
- lack of a robust evidence base; being mindful that the majority of referrals to the adult gender clinics are of natal females who are aged between 17 and 25 years, and that the historical evidence base that has informed clinical practice relates to an older cohort of natal males;
- limited information on short and long-term outcomes, particularly for those individuals who transferred to adult services from paediatric services;
- an increasing incidence of individuals seeking to 'detransition' following previous gender affirming interventions and the absence of a consistent, defined clinical approach for them.

In her final report, Dr Cass has also expressed significant disappointment and concern that it had not been possible during the lifetime of the review to progress a key plank of its research programme due to a lack of cooperation from the adult GDCs. As you will recall from our previous correspondence on this matter, the Secretary of State for Health and Social Care granted an order under s22(5) of the Gender Recognition Act to enable data to be disclosed for a time-limited period for the sole purpose of the data linkage study established by the Cass Review and that proposal received full approval from the Health Research Authority. Like all NHS research, the study is subject to strict ethical and legal controls with an 'opt out' option for individuals who do not wish to have their data used as part of the study.

The study relied upon your organisations fully cooperating with the University of York in support of the research. However, despite the best efforts of the research team, the necessary cooperation from the clinical leads within the Gender Dysphoria Clinics was not forthcoming, despite - and contrary to - positive assurances from CMOs. Consequently, the University of York advised that it was unable to begin the next stage of the study.

If left this way, it would represent a missed opportunity for the NHS to lead the way internationally in gathering high quality evidence that can, for the first time, present a better understanding of the longer-term outcomes for individuals who have received clinical or medical intervention for gender dysphoria / gender incongruence in childhood or adolescence. It is for this reason that NHS England has agreed to pick up responsibility from the Review for progressing the data linkage study, with oversight from our National Research Oversight Board, and we will work closely with you to ensure this happens.

Service Review, Review of Service Specification, and Clinical Policy

Dr Cass recommended that the review of the adult service specification should be brought forward. We had already taken that decision in light of our own concerns and that work will kick off this month as planned. However, in light of the broader issues that Dr Cass has highlighted we have taken the decision that a more systemic review of the operation and delivery of the adult GDCs would be appropriate. We envisage the deployment of external quality improvement experts into the services at a formative stage of the review process and will share more details with you shortly, including a broad timeline.

We will also define the role of gender affirming hormones through the development of a new evidence based national clinical policy which will cover all people over the age of 16. Again, details on the procedure to be followed in its development will follow.

Immediate Actions

In terms of immediate next steps and actions, we would ask the following:

- that you support discussions at Board level and with your adult GDCs on the findings and recommendations set out in the final Cass Review report and their relevance to the adult service.
- you prepare your adult GDCs to fully participate with the data linkage study and avoid the need for mandatory direction in this respect. Further details will be communicated shortly.
- defer offering first appointments to patients until their 18th birthday as an immediate response to Dr Cass's advice that 'extreme caution' should be exercised before making a recommendation for gender affirming hormones in young people under 18 years of age.
- ensure adult gender clinics are meeting the requirements of the current service specification, particularly with regard to the assessment process and for those individuals with complex presentations.

We look forward to working with you as we take forward these important reviews of the adult gender services. We will be in contact again shortly with further details on our approach.

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