



Independent review
into gender identity
services for children
and young people

Dr Hilary Cass
Chair
Independent Review of Gender Identity
Services for Children and Young People

National Director
Specialised Commissioning
NHS England

Sent by email

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Dear John

As the Review moves into its final phase, I thought it would be helpful to provide an update on progress since my last letter, to outline the Review timetable going forward, and highlight some areas in which NHS England (NHSE) and colleagues across the system may be able to help achieve the Review's objectives.

Over the last few months, the Review has continued to engage with key stakeholders across the statutory and voluntary sectors, as well as leaders of professional organisations, and I have had ongoing listening sessions with individuals who have direct service experience. The Review's commissioned research team is making excellent progress with the systematic reviews, a review of existing guidelines, an international survey of services in countries with comparable healthcare systems, and the qualitative research. We will have outputs from these pieces of work by the spring. I have also established a Clinical Expert Group, including representatives of professional bodies, NHSE's phase one provider units, gender experts and others with expertise in children and young people's care, to help us interpret the findings of this research. Alongside this, the Review is engaging with service users to gain insight into their perspectives on these initial findings.

We have discussed previously the fact that the commissioned data linkage study (part of our quantitative research programme), which represents a unique opportunity to collect longer-term outcome data on this population, has been much more complex than initially envisaged, and is taking longer to establish. However, I am pleased to say that we have now received provisional approvals and will soon be moving into the next phase of the work, which will involve detailed information for service users and the option to opt out before commencement of any data collection. The full protocol will be published on our website.

I anticipate that by the summer, in addition to the strands of work described above, we will have some information on the intermediate outcomes for children and young people with gender dysphoria, as well as the changing characteristics of this group, using data which is already routinely collected within the NHS. However, the complexities encountered in establishing the data linkage study means that the full results of this element will likely not be available before the Review is concluded. As you know, we have already had discussions about the logistics of establishing a formal research network (as described in my [letter of July 2022](#)) to receive the results of this study, oversee a clinically informed future research programme and ensure translation into clinical practice.

In the interim, I would like to ask for your help in obtaining some existing data which is of more immediate importance to understanding the needs of this population:

- Firstly, to-date the Review has been working on the understanding that around 20% of children and young people seen by the Gender Identity Development Service (GIDS) enter a hormone pathway. At this stage, it is crucial for us to verify that this is an accurate assumption as it has significant bearing on getting a fuller understanding of the outcomes of the existing clinical approach. I anticipate that it should be relatively straightforward to clarify this through an audit of discharge summaries and would be grateful if this could be arranged as swiftly as possible with colleagues at GIDS.
- Secondly, I understand from discussions with clinicians, that there has been a significant change in the demographic of referrals to adult NHS Gender Dysphoria Clinics (GDCs) - from a more mixed group in terms of age and birth-registered gender to a population base where a significant majority are under 25, with a higher proportion of birth registered females. This obviously comprises a mix of referrals from GIDS and direct referrals to adult clinics. I would be grateful if more robust data on this could be obtained since it is relevant for thinking about both the transition of young people to adult services and potential unmet need within the children and young people's service.

In terms of broader support, there are a number of strands of work which are outside our control, but are crucial to the successful delivery of the Review:

- I would particularly like to thank NHS-Digital for their help to-date in moving forward on the data linkage and look forward to continuing to work with them on this.
- I also look forward to working with the adult NHS GDCs, which are a vital part of understanding the patient journey.

The Review will continue to share information as it becomes available, and I anticipate submitting a final report to NHSE by the end of the year. Within that, I will be making clear those issues we consider to be the sole responsibility of the healthcare system and signposting other issues which fall outside the responsibility of the NHS and require the input of other agencies and organisations and I will make recommendations accordingly.

Yours sincerely

A handwritten signature in black ink that reads "Hilary". The signature is written in a cursive style with a large, looped 'y' at the end.

Dr Hilary Cass
Chair, Independent Review of Gender Identity Services for Children and Young People