



Assessment, Management and Outcomes for children and young people referred to the National Gender Identity Development Service

Information for those who have attended Adult Gender Identity Clinics only

Why is this study important?

We know little about what happens to children and young people who have accessed the Gender Identity Development Service (GIDS), some of whom are now adults. We need to know more about what support they received and whether this support has helped them. This will ensure we have the best possible evidence when providing care. It will also help young people and parents make decisions.

What information will we be looking at?

We want to know about the process that **all children and young people** have been through, from the point at which they were referred to GIDS right through to the point they are now. This pathway will be different for every child and young person.

We want to know more about what support and which interventions made a difference. This means we would like to collect information from four different sets of records:

1. Medical records at the Tavistock Gender Identity Development Service
2. Medical records at Endocrine services
3. Hospital admission and Accident and Emergency information held by NHS Digital Data and Analytics
4. Medical records from Adult Gender Identity Clinics

When looking at these records we are interested in the following information on patients: who referred them to the clinic; any health conditions they may have; information about their family structure; information about their mental health; information about psychosocial support accessed; whether they accessed clinic support and any prescriptions they have had, including use of hormones and any other medication. We may also see, but are not interested in, directly identifiable information, for example their name or whether they have a Gender Recognition Certificate. We will not record this information.

Data from patient records will be linked together by the NHS Data and Analytics team. We understand the sensitivity of this information and have taken a number of steps to limit who can see this information and to ensure that those who can are subject to strict confidentiality requirements. There is further information about this below.

Why are my data included if I haven't attended the Tavistock Gender Development Service for Children and Young People?

It is not possible to identify all young adults who have previously attended the GIDS service from data held at the Tavistock. We therefore also need to use data for all those born between 1990 and 2002 who have attended an adult gender clinic, to see if they previously accessed children's services.

Who will see my records?

Staff from the adult gender clinics will securely share information that will identify you to NHS Data and Analytics – this information will be your NHS number(s), gender, date of birth and postcode. NHS Data and Analytics will then try to match this information with information obtained from the Tavistock GIDS service. If you have not attended the Tavistock GIDS service your data will not match and will be securely destroyed at this point. The research team at the University of York will not see any information for anyone who does not match to the GIDS cohort.

For people who have attended the Tavistock GIDS service, research assistants working for the University of York will extract additional clinical data from both their GIDS medical notes and adult gender clinic notes. They will see identifiable data including name, address and date of birth. However, they are not interested in any information that identifies anyone and will not record this. Only the research assistants will have direct access to patient notes, and they will be working under strict rules of confidentiality. Data sent back to the University of York by the research assistants for analysis will include information about received care but will not include any information that identifies individuals.

Research assistants responsible for extracting clinical data from medical notes will not be involved in analysing the data and will not have access to the final dataset held at the University of York. Similarly, researchers at the University of York responsible for analysing the data will not have direct access to medical notes.

The Cass Review team, who have asked for this research to be done, will not see anyone's records.

What will the findings be used for?

Findings will ensure children and parents have access to the best possible information, when making decisions about care. The findings will also help the CASS Review team to identify the best possible care pathways for children and young people who need support around their gender identity.

Do I have a choice about my records being included?

It is important that we capture what happens to **all children and young people**; this will ensure we have as much information as possible to enable young people to make decisions about their care. Because we need to look at a large number of records (about 9000 in total), it is not possible to get individual, retrospective consent. However, you do not have to be involved in this study if you do not want to.

What do I do if I don't want my information to be included as part of this study?

If you do not want your records to be included in this research, please contact your Adult Gender clinic by **Monday 12 February 2024**.

Anyone who has already opted out of their data being used from research via the national data opt out (<https://digital.nhs.uk/services/national-data-opt-out>) will not be included in this study. Opting out of this study will not impact your clinical care.

Who decided that this study can happen?

The ethical aspects of this study have been reviewed and approved by a *Research Ethics Committee* of the Health Research Authority (22/HRA/3277). The use of confidential patient data without consent has been approved by the Health Research Authority following advice by the Confidentiality Advisory Group (CAG). CAG is an independent body which provides expert advice on the use of confidential patient information (REF 22/CAG/0129).

In order to link together information from before and after their transition, for individuals who have a gender recognition certificate, an amendment (known as a *Statutory Instrument*) to the Gender Recognition Act was required. The amendment ensures that the research does not inadvertently breach the Act. It does this by providing for a limited exemption, for a closely defined group of people (i.e. those involved in this research), to facilitate, assist and carry out the research without risking criminal liability (for more information, see: <https://www.legislation.gov.uk/uksi/2022/742/made>). The amendment does not allow for any onward disclosure of this protected information, or for the use of this protected information for anything other than the Cass Review. Neither this amendment nor the data created for this study can be used for any other purposes, and the data held in this dataset will be securely destroyed once the research is complete.

Where can I find out more about this study?

More information about the study and how your personal data will be handled and kept safe by the NHS Data and Analytics team and researchers at the University of York can be found here:

- The Cass Review research programme: <https://cass.independent-review.uk/research/>
- NHS Data and Analytics data security: <https://bit.ly/3Nn13rn>
- University of York privacy notice: <https://www.york.ac.uk/records-management/dp/your-info/privacynotice-researchparticipants/>

The research team at the University of York can be contacted at: cass-review@york.ac.uk

Study sponsor and data controller – The University of York