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Improving the experience of health services for trans and gender-diverse young people and their families: an exploratory qualitative study

Submission date
16/11/2018

Recruitment status
No longer recruiting

Registration date
30/11/2018

Overall study status
Completed

Last Edited
13/02/2025

Condition category
Other

[X] Prospectively registered
[_] Protocol
[_] Statistical analysis plan
[X] Results
[_] Individual participant data

Plain English summary of protocol

Background and study aims
In the United Kingdom, trans young people find themselves at the centre of political storms and debate regarding their access to health care and treatment. This research was carried out against a backdrop of increasing evidence of repeated failings in health care for trans people. Compounding this, trans young people face lengthy waiting lists when seeking specialist gender services and problems with the referral process. In order to cope and thrive, online resources and spaces have become increasingly important for trans young people. Finding good-quality resources and information can be difficult for young people and families.

Who can participate?
Gender-diverse young people and adults (aged over 12 years), non-paired families, GPs and Child and Adolescent Mental Health Service (CAMHS) professionals (and other 'gateway' health professionals)

What does the study involve?
Interviews with the participants will be recorded by audio and video. The interviewers will aim to find out the participant's views and experience of gender identity health services, as well as their broader experiences of living trans, non-binary and/or gender diverse. The participant interviews will be used to inform the development of two new sections of Healthtalk.org, a website that provides personal perspectives on different health issues. The sites will be evaluated using the e-hiq questionnaire.

What are the possible benefits and risks of participating?
Given the nature of this study, it is unlikely that participants will suffer harm by taking part. However, the impact of being interviewed can differ for each person. Therefore, each interview participant will be offered further sources of help and information after the interview should they require this – this list will likely include the Mermaids helpline and Mindline Trans+ support helpline – further sources of help will be decided in collaboration with the Advisory Group. The main beneficiaries of the research are likely to be the children and young people (and families) preparing to attend specialist services and/or those who are gender diverse.

Where is the study run from?
University of Oxford (UK)

When is the study starting and how long is it expected to run for?
June 2018 to February 2022

Who is funding the study?
National Institute for Health Research (UK)

Who is the main contact?
Dr Melissa Stepney

Contact information

Type(s)
Scientific

Contact name
Dr Melissa Stepney

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Additional identifiers

Integrated Research Application System (IRAS)
112111

Central Portfolio Management System (CPMS)
13550

Protocol serial number
17/51/07

Study information

Scientific Title
Improving the experience of health services for trans and gender-diverse young people and their families: an exploratory qualitative study

Study objectives

Current study hypothesis as of 12/02/2025:
Our aim was to improve the care and support of gender-diverse youth, and their families, through identifying improvements to National Health Service care and services. To achieve this, our objectives were to gain a better understanding of the experiences of trans youth, family members and health professionals; and to develop and evaluate sections of the Healthtalk website on young people and parent/carer experiences.

Ethics approval required
Old ethics approval format

Ethics approval(s)
NRES Committee South Central – Berkshire, 11/09/2012, ref: 12/SC/0495
Our studies do not require NHS sites to act as 'Research Sites' (under the new National Research Ethics service guidelines), but only as 'Participant Identification Centres (PICS)'. Research that is conducted using these methods and for dissemination on Healthtalk is included on the National Institute for Health Research Network (NIHR CRN) Portfolio (IRAS Ref: 112111. Study ID: 13550).

Primary study design
Observational

Study design
Qualitative observational and exploratory study

Study type(s)
Quality of life

Health condition(s) or problem(s) studied
Gender identity/diversity/variance

Interventions
Current interventions as of 12/02/2025:
1. Video and audio recorded in-depth narrative interviews with a diverse nationwide sample of 40 gender-diverse young people (aged 12-25 years)
2. 10 young adults over the age of 25 years
3. 20 (non-paired) family members
4. Audio recorded interviews with 20 “gateway” professionals (GPs, CAMHS professionals)

Interviews will take place in people’s own homes, or another location if the participant prefers, using methods that have already been approved for national studies by an NHS ethics committee. The interviews will be video or audio-recorded (according to the participant’s preference) and will invite people to talk about their experiences of health and healthcare including perceptions of current service provision. The interviews we conduct for this project will cover a broad range of experiences and perspectives, not just of healthcare experiences but also wider experiences of living transgender, including schooling, work and careers; friends and family relationships; leisure; sense of self and body image; planning for the future; sources of support and information. We want to find out about the experiences and priorities of the transgender community and the interviews will therefore resemble a guided conversation in which the researcher has a list of possible topics and prompts rather than structured questions.

The researcher will conduct the interview either in one session or two, depending on the preferences and energy levels of the participants and how long they would like to talk. Interviews are anticipated to be between 45 minutes to several hours.

The impact of HealthTalk resources will be measured through an adapted version of the e-HIQ evaluation tool with young people and families to explore how useful they found the resources. Participants will be given a link to access the 'draft' site which they will be able to use for as long and as frequently as they like during a 24-hour period; before taking part in a focus group to explore their views of the sites, specifically as a source of information and emotional support for people waiting for specialist services.

Intervention Type
Other

Primary outcome(s)
1. Understand the perspectives and experiences of young people, families and 'gateway' professionals (GPs, child and adolescent mental health professionals, gender identity clinic clinicians) in gender identity health services.
2. Identify ways in which specialist gender identity services can be improved and develop resources to help achieve these improvements.

Key secondary outcome(s)
1. Conduct a formative evaluation of the two new Healthtalk sections, using a validated questionnaire as a basis, to assess the role of those resources as a source of information and emotional support for people waiting for specialist services.

Completion date
28/02/2022

Eligibility

Key inclusion criteria
Current inclusion criteria as of 12/02/2025:
Gender-diverse young people:
1. Aged 12-25 years

Gender-diverse young adults:
2. Aged 25-35 years

Non-paired family members:
3. Parents/carers or family members of gender-diverse young people

Health professionals:
4. Practising GPs and Child and Adolescent Mental Health Service (CAMHS) professionals
5. Formative evaluation participants - trans/gender diverse young people & family members (parents/grandparents)

Participant type(s)
Patient, Health professional, Carer, Learner/student, Other

Healthy volunteers allowed

No

Age group
Mixed

Sex
All

Total final enrolment
95

Key exclusion criteria
Does not meet inclusion criteria

Date of first enrolment
01/04/2019

Date of final enrolment
10/02/2022

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
University of Oxford
Nuffield Department of Primary Care Health Sciences, University of Oxford,
Radcliffe Observatory Quarter, Woodstock Road
Oxford
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Study participating centre
(Formerly) Gender Identity Development Service, Tavistock and Portman NHS Foundation Trust
120 Belsize Lane
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Sponsor information

Organisation
University of Oxford / Clinical Trials and Research Governance

ROR
https://ror.org/052gg0110

Funder(s)

Funder type
Government

Funder Name
National Institute for Health Research

Alternative Name(s)
National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan
The datasets generated during and/or analysed during the current study are not available due to the sensitivity of the topic.

IPD sharing plan summary
Not expected to be made available

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Results article		09/02/2025	10/02/2025	Yes	No
Results article	Full report		12/02/2025	Yes	No
Results article	Full report		13/02/2025	Yes	No
HRA research summary			28/06/2023	No	No
Other publications			12/02/2025	Yes	No

Other publications			12/02/2025	Yes	No
Other publications			12/02/2025	Yes	No
Plain English results			13/02/2025	No	Yes
Study website	Study website	11/11/2025	11/11/2025	No	Yes