ISRCTN26256441 https://doi.org/10.1186/ISRCTN26256441

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	☒ Prospectively registered ☐ Protocol ☐ Statistical analysis plan ☒ Results ☐ Individual participant data
Registration date 30/11/2018	**Overall study status** Completed	
Last Edited 13/02/2025	**Condition category** Other	

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

Study website
https://healthtalk.org/introduction/experiences-trans-and-gender-diverse-young-people/

Contact information

Type(s)
Scientific

Contact name
Dr Melissa Stepney

ORCID ID
http://orcid.org/0000-0001-8743-9443

Contact details
Nuffield Department of Primary Care Health Sciences, University of Oxford,
Radcliffe Observatory Quarter, Woodstock Road
Oxford
United Kingdom
OX2 6GG

Additional identifiers

EudraCT/CTIS number

IRAS number
112111

ClinicalTrials.gov number

Secondary identifying numbers
17/51/07, IRAS 112111, CPMS 13550

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).

Study design

Qualitative observational and exploratory study

Primary study design

Observational

Secondary study design

Qualitative

Study setting(s)

Community

Study type(s)

Quality of life

Participant information sheet

Not available in web format, please use contact details to request a participation information sheet.

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 measure
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.

Secondary outcome measures
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.

Overall study start date
19/06/2018

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

Age group
Mixed

Sex
Both

Target number of participants
90

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
England

United Kingdom

Study participating centre
University of Oxford
Nuffield Department of Primary Care Health Sciences, University of Oxford,
Radcliffe Observatory Quarter, Woodstock Road
Oxford
United Kingdom
OX2 6GG

Study participating centre
(Formerly) Gender Identity Development Service, Tavistock and Portman NHS Foundation Trust
120 Belsize Lane
London
United Kingdom
NW3 5BA

Sponsor information

Organisation
University of Oxford / Clinical Trials and Research Governance

Sponsor details
Joint Research Office
1st Floor, Boundary Brook House
Churchill Drive
Headington
Oxford
England
United Kingdom
OX3 7GB
00000 000000
ctrg@admin.ox.ac.uk

Sponsor type
University/education

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

Publication and dissemination plan

Dissemination routes will include two new Healthtalk sections - which had 5.7 million visitors in 2017 - and other social media platforms including Twitter and Facebook, specialist clinics and more traditional academic publications and conference presentations. Co-applicants and participants in the national networking event will help to co-produce recommendations and resources to help health and care staff to respond effectively to young people and their families. Dissemination activities are scheduled March to June 2021.

Intention to publish date

14/02/2022

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?
HRA research summary			28/06/2023	No	No
Results article		09/02/2025	10/02/2025	Yes	No
Other publications			12/02/2025	Yes	No
Other publications			12/02/2025	Yes	No
Other publications			12/02/2025	Yes	No
Results article	Full report		12/02/2025	Yes	No
Plain English results			13/02/2025	No	Yes
Results article	Full report		13/02/2025	Yes	No