

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

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**Disclaimer:** This report contains transcripts of interviews conducted in the course of the research, or similar, and contains language which may offend some readers.

This report was written during 2022–3 prior to the final Cass Report recommendations and during a period of significant uncertainty in trans health care.

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## Scientific summary

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# Scientific summary

## Background

In the United Kingdom, trans young people find themselves at the centre of a number of devastating political storms regarding their access to health care and treatment. This research was carried out against a backdrop of evidence of repeated failings in health care for trans people.

Anti-trans sentiments have influenced high-profile discussions and policy decisions about the appropriateness of medical interventions, including puberty suppressant treatment. Compounding this, trans young people face lengthy waiting lists when seeking access to specialist gender services, with delays and problems with the referral process. The lack of access to appropriate health care has a profound impact on young trans people. Trans young people often experience higher rates of psychological and social difficulties resulting (in)directly from prejudice and discrimination, gender dysphoria and social pressures.

The recent decision to restructure gender services for young people, and close the long established Gender Identity Development Service at the Tavistock and Portman NHS Foundation Trust, is leading to further uncertainty. In order to cope and thrive against so many challenges, online resources and spaces have become increasingly important for trans youth. Finding good-quality resources and reliable information can be difficult for young people and families amid so much misinformation. Previous research also suggests that little is documented about the journeys that trans young people go through and their families experience in finding clinical care.

## Objectives (research questions)

The objectives that the research sought to investigate were:

- What are the perspectives and experiences of gender-diverse young people, families (parents/carers) and health professionals who work with gender-diverse patients?
- From these experiences, what improvements can be made to NHS services, including specialist gender services?
- How can supportive resources to help achieve these improvements best be developed?
- What do young people and families who have experience of being on the waiting list for specialist gender services think about the resources developed?

## Methods

The primary method of data collection was qualitative semistructured in-depth interviews. A qualitative approach allows us to gain a better understanding of young people and families' experiences, and an insight into their journeys through different services, as well as the wider social, economic and cultural processes that shape those journeys. Qualitative approaches do not merely examine outcomes and end destinations but also the journeys and processes involved. Narrative interviews allow participants to tell the stories that are meaningful to them.

In total, 91 interviews were conducted between 2019 and 2021 with 50 with young people (42 aged 13–24 years and 10 young adults aged 25–35 years), 19 family members of gender-diverse young people (parents/carers) and 20 health professionals working with trans patients. A purposive recruitment method was employed for a maximum variation sample. Participants were recruited through co-applicant and

advisory group networks, social media; local and national support groups; and snowballing. A broad range of cisgendered and trans health professionals were recruited to the study, including general practitioners (GPs), practice nurses, counsellors and mental health practitioners. Young people in the study identified as trans girls/women/femme, trans boys/men/masc, non-binary, gender-queer/fluid, androgyne, bi-gender. Parents had a wide range of views and experiences with healthcare providers (primary, mental health and specialist gender identity services). Participants came from a variety of socioeconomic backgrounds and were recruited from both rural and urban areas across England, Wales and Scotland. Approximately 38% of our young people sample were from a minority ethnic group.

Interviews were digitally audio- or video-recorded (depending on the participant's preference), transcribed by a professional transcriber, checked by the researcher and a research assistant, and sent to the interview participant for checking. Analysis was conducted using NVivo software (QSR International, Warrington, UK) to code different aspects of people's accounts and to group similar themes (thematic analysis) across all of the interviews. Recurrent themes and subthemes were thus identified as they emerged from the data. The method of constant comparison was used to ensure that the main perspectives on the issues that are important to participants were included.

Although the study was exploratory rather than definitive, several factors enhanced the validity of the findings, in particular, the comprehensive breadth and range of participants, including participants that could be defined as outliers, the in-depth nature of the interview process, the rich descriptions of peoples' experience of services, the checking and validation of findings by research team members and external sources, the sharing of findings with participants (to achieve a degree of respondent validation), and the triangulation of the data. All procedures were accurately documented and re-examined at every stage of the research.

## Results

Four key domains that prevent trans and gender-diverse young people receiving good-quality care were identified from our analysis of the interviews with health professionals: structural, educational, cultural and social, and technical barriers. Health professionals highlighted the shortage of services, long waiting times, lack of guidelines and lack of funding and support. All professionals, particularly GPs and nurses, thought that trans health was not sufficiently covered by their education and professional training. Health professionals spoke about negative attitudes and prejudice towards trans people in their own professions. Most participants identified challenges related to their and others' communication, with language around trans and gender-diverse identities, pronouns and titles, and lack of cultural competency. Finally, technical and administrative issues created further barriers to providing good-quality care. Inflexible computer systems and, display systems in waiting rooms meant exclusions on a number of levels, including missing necessary check-ups and scans alongside unnecessary misgendering.

The healthcare experiences of parents/carers are marked by multiple challenges. These occur at all stages of the pathway and range from getting a referral to specialist gender services, lack of support during waiting times through to sometimes unclear and lengthy assessment processes, which many participants experience as 'gatekeeping' of gender-affirming care. These can have a negative impact on the young person and their loved ones. Parents/carers described a lack of understanding and knowledge of trans identities and health in primary healthcare professionals and Child and Adolescent Mental Health Service, which led to delay of referrals and at times treatment. They also spoke of trans-negative attitudes and prejudice among healthcare professionals, as well as cisnormativity. It was felt there was a scarcity of specialist services with resultant long waiting times that leave families waiting and unsupported for years. Parents felt there was gatekeeping of gender-affirming interventions and a lack of clarity about the assessment process within gender specialist services.

Our analysis of the young people data set showed how young people felt the current healthcare system does not cater for the diversity of trans identities and needs.

Young people often feared they were ‘not trans enough’ when approaching healthcare professionals for help. The threshold for trans patients was felt to be too high, with models of trans health care based on outdated, psychiatric/medicalised and pathologising ideas. Indeed, young people perceived NHS services as being built around a culture of pathologisation, gatekeeping and trans hostility, resulting in a general level of mistrust in health services. As a consequence, young trans people can be anxious when approaching health professionals for help. Compounding this fear is the lack of knowledge and expertise that young people report when encountering health professionals. This included a lack of understanding of shared care agreements, the impact and effect of hormones, and referral processes for gender specialist services. Quality of care is variable at best, with young people (like parents) often acting as educator and researcher, relaying knowledge to a health professional. This created large amounts of preparation, emotional energy and investment for a young person before going to a consultation.

While we identified pockets of good care with some notable examples, medical professionals sometimes assumed too much about trans young people and knew too little. Young people felt that they were experts on their own bodies concerning how they react and feel. What young people wanted to see, was less hierarchy in their encounters with health professionals and more equitable, shared decision-making, based around an informed consent model. They wanted to work in partnership with healthcare professionals based upon an equal relationship that recognised their autonomy and expertise over their own bodies.

A linear, one-dimensional, conception of gender identity informed services experienced as restrictive and failing to reflect gender identity experiences among young people where there can be a plurality and fluidity of experiences. Non-binary needs, for example, are often bypassed/not catered for in NHS services. Young trans people of colour and those who are neurodiverse face additional barriers and discrimination in healthcare services.

All young people spoke about the wider trans-hostile environment in the UK and how they felt the circulation of harmful and damaging media stories influenced the care that they received. It was frustrating and angering when their lives (and medical care) were sensationalised leading to dangerous fear mongering. Prejudiced stories about trans youth were often at odds with participants’ experiences.

Young people used a number of strategies to cope, including online communities and charities, which provided a lifeline for some. Many participated in ‘mutual aid’ where there were reciprocal relationships of help between friends and communities. Counselling and communal support were also important to improve young people’s well-being. This often involved coming to accept themselves and take pride in their identities.

## Healthtalk resource

From the categories and themes in the research data, a series of ‘topic summaries’ on the issues were written to produce the Healthtalk resources (<https://healthtalk.org> – search ‘trans’). Over 30 summaries for each data set (parents/carers and young people) were written. The resources go through a rigorous process of editing and checking. For each section, there are 200–300 audio/video clips of young people and parents talking about their experiences. Both sites are written with a non-academic audience in mind, and have a wide reach appealing to trans and gender-diverse young people and their families, the wider public, media, teachers, researchers and policy-makers.

## Evaluation

These resources were evaluated by 19 young gender-diverse people and family members (aged 15–69 years). We ran six focus group sessions over a 2-week period, with participants asked to provide

in-depth feedback on the design, content, usefulness and acceptability of the resources. Feedback found that the depth and complexity of the resources generated by the project will help to ensure that they remain relevant. Evaluation participants strongly commended the comprehensiveness, balance and optimism of the online resources. Participants valued the range and diversity of experiences reflected in the resources in terms of age, where somebody was in their transition, ethnicity and gender. Overall, participants felt they could relate to the stories and experiences in the resources generated by the research.

Future research areas raised during the evaluation were the experiences of homeless trans young people, siblings, grandparents and those in care or care leavers. In light of the ongoing restructuring of gender services, a thorough service evaluation in partnership with trans organisations to assess the reorganisation is vital.

## Conclusions

We make five recommendations for health care:

1. Empowered decision-making for trans young people.
2. Recognise and cater for diverse needs.
3. Baseline and mandatory trans positive training for all health professionals.
4. A restructured, depathologised service developed in partnership with trans-positive gender specialists.
5. The NHS should contribute positively to public debate and challenge misinformation, providing 'official' information sources that have been co-produced with the trans community.

Taken together, these recommendations will create more inclusive health services that will help to counteract the alienation and hostility that gender-diverse young people and their families currently face.

## Study registration

This study is registered on the ISRCTN Registry as ISRCTN26256441.

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