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Health and Social Care Delivery Research

Volume 13 • Issue 4 • February 2025

ISSN 2755-0079

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DOI 10.3310/XCYT6530

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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.

Published February 2025
DOI: 10.3310/XCYT6530

This report should be referenced as follows:

Stepney M, Martin S, Mikulak M, Ryan S, Stewart J, Ma R, Barnett A. Improving the experience of health services for trans and gender-diverse young people and their families: an exploratory qualitative study. *Health Soc Care Deliv Res* 2025;**13**(4). https://doi.org/10.3310/XCYT6530

Health and Social Care Delivery Research

ISSN 2755-0079 (Online)

A list of Journals Library editors can be found on the NIHR Journals Library website

Health and Social Care Delivery Research (HSDR) was launched in 2013 and is indexed by Europe PMC, DOAJ, INAHTA, Ulrichsweb™ (ProQuest LLC, Ann Arbor, MI, USA), NCBI Bookshelf, Scopus and MEDLINE.

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: journals.library@nihr.ac.uk

This journal was previously published as *Health Services and Delivery Research* (Volumes 1–9); ISSN 2050-4349 (print), ISSN 2050-4357 (online)

The full HSDR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/hsdr.

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This article

The research reported in this issue of the journal was funded by the HSDR programme or one of its preceding programmes as award number 17/51/07. The contractual start date was in January 2019. The draft manuscript began editorial review in September 2022 and was accepted for publication in June 2024. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HSDR editors and production house have tried to ensure the accuracy of the authors' manuscript and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this article.

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Abstract

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

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Background: 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.

Objectives: 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. Within this overall aim, 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.

Methods: The primary method of data collection was qualitative in-depth interviews conducted between 2019 and 2021. In total, 91 interviews were conducted with 50 young people (42 aged 13–24 years and 10 aged 25–35 years), 19 family members (parents/carers) and 20 health professionals working with trans patients. We evaluated the resources with young people and families who have experience of being on the waiting list for specialist gender services.

Results: From interviews with health professionals, we identified four key domains that prevent trans and gender-diverse young people receiving good-quality care. These were structural, educational, cultural and social, and technical barriers. Parents/carers' healthcare experiences were marked by multiple challenges. These occurred 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 experience as gatekeeping of gender-affirming care.

The majority of the young people in our sample felt the current healthcare system does not cater for the diversity of trans identities and needs. A linear, one-dimensional, conception of gender identity informs services. This is restrictive and does not reflect the plurality and fluidity of experiences. Young people we spoke with generally perceived National Health Service services as built around a culture of pathologisation, gatekeeping and trans hostility, resulting in a general level of mistrust.

The research supported the development of two sections of the Healthtalk website concerning young people and parent/carer experiences.

Conclusions: We make five recommendations: (1) better and empowered decision-making for trans young people; (2) recognising and catering for gender diversity in health care; (3) a 'systems change' intervention approach that goes beyond training for individual health practitioners; (4) a restructured service based upon informed consent; and (5) a positive role for the National Health Service in public debate, challenging misinformation. These findings have wider applicability to other settings/services such as education and social work.

Limitations: This research was not a service evaluation and did not evaluate current practice in Gender Identity Development Service or Gender Identity Clinics. The research was conducted in a rapidly changing field where specialist gender services for children and adolescents are undergoing significant changes based on the Cass review recommendations, which might render some service-specific information out of date.

Future work: An evaluation in partnership with trans organisations to assess the reorganisation of specialist services. Research on homeless trans youth, sibling and grandparent experiences, and trans youth in care/care leavers.

Study registration: This study is registered on ISRCTN Registry ISRCTN26256441.

Funding: This award was funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme (NIHR award ref: 17/51/07) and is published in full in *Health and Social Care Delivery Research*; Vol. 13, No. 4. See the NIHR Funding and Awards website for further award information.

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Glossary

Agender Identifies with no gender.

Asexual A variation in levels of romantic and/or sexual attraction, including a lack of attraction.

Bigender Identifies with more than one gender.

Binder/binding Item of clothing worn by trans men and transmasculine people. Mermaids describe binding as ‘used by some (but not all) trans masculine people to compress their chests and create a more conventionally masculine shape’ [Mermaids. *Glossary*. Mermaids; 2021. URL: https://mermaidsuk.org.uk/glossary/ (accessed January 2022)].

Bisexual Romantic and/or sexual orientation towards more than one gender.

Bottom surgery A way of referring to surgery that alters the genital region.

Cisgender A cis/cisgender/cisperson, is a person whose gender identity is the same as the sex they were assigned at birth.

Dead name A previous name, such as a birth name, that a trans or gender diverse no longer goes by.

Deadnaming The act of referring to a trans or gender-diverse person by their previous name, such as a birth name, that they no longer go by.

Enby Abbreviation of non-binary (a way of saying ‘nb’).

Facial feminisation surgery Surgery to make your face a more feminine shape.

Gatekeeping Sometimes used to describe health professionals limiting and/or controlling the access to medical interventions for trans and gender-diverse patients. Is often felt to be based on strict criteria related to gender expression and/or presentation or childhood history of gender dysphoria.

Gay Refers to men who have a romantic and/or sexual orientation towards men.

Gender diverse This term may describe a group of individuals who do not identify as completely male or female and who may use descriptors such as non-binary, genderqueer, and/or transgender; individuals who express gender nonconformity but do not necessarily ascribe to a transgender identity; and/or individuals whose gender identities might not align with either the female/male binary.

Gender dysphoria/gender incongruence Describes the distress felt by trans and gender-diverse people due to an incongruence [mismatch] between their sex assigned at birth and their gender identity.

Gender euphoria Describes feelings of joy, comfort and satisfaction when trans and gender-diverse people express and are affirmed in their gender identity.

Genderfluid Describes a fluid conception of gender that shifts, changes or transforms over time.

Gender nonconformity Not conforming to gender norms or roles.

Genderqueer An umbrella term for people who identify with, embrace/reject multiple, none, any, both/neither gender, or moving in-between or outside of genders throughout time. Can align with the political challenge/subversion of gender norms. See also non-binary.

Gender Identity Clinic Adult gender identity services based in different locations in England.

Gender Identity Development Service Service at the Tavistock and Portman National Health Service Foundation Trust.

Hormone blockers Gonadotrophin-releasing hormone analogues. These are synthetic (human-made) hormones that suppress the hormones naturally produced by the body.

Hormone therapy Cross-sex hormone treatment; hormone therapy for adults means taking the hormones of your preferred gender: a trans man will take testosterone (masculinising hormones), a trans woman will take oestrogen (feminising hormones).

Informed consent Often described as a model/approach to transgender health care. (1) Promotes a departure from the use of the diagnosis of gender dysphoria as a prerequisite for accessing transition services and (2) attempts to impact the way that trans-gender individuals experience and access health care by removing the psychotherapy/gatekeeping requirement (Schulz SL. The informed consent model of transgender care: an alternative to the diagnosis of gender dysphoria. *J Humanist Psychol* 2018;**58**:72–92. https://doi.org/10.1177/0022167817745217).

Intersex A term used to describe a person who may have the biological attributes of both sexes or whose biological attributes do not fit with societal assumptions about what constitutes male or female. Intersex people may identify as male, female or non-binary.

Lesbian Refers to women who have a romantic and/or sexual orientation towards women.

Meme A humorous video, image, GIF (graphics interchange format) or text shared online through social media.

Non-binary An umbrella term for people whose gender identity does not sit comfortably with binary concepts of gender such as man/woman, male/female. Non-binary identities are varied and can include people who identify with some aspects of binary identities, while others reject them entirely. See also genderqueer and gender-diverse.

Pass/ing When a trans person is perceived as the gender they wish to be seen as.

Pronouns Gender pronouns (e.g. he/she/they) are used to refer to the sex and/or gender of a person. Changing and using different pronouns can be part of a trans or gender-diverse person's journey.

Queer Refers both to 'queer theory' as a political movement in the late 1980s/early 1990s, challenging and subverting gender and sexuality norms as well as an umbrella for wider lesbian, gay, bisexual, trans, queer+ identities.

Section 28 Section 28 of the Local Government Act 1988 banned local authorities and schools from 'promoting homosexuality' or 'publishing material with the intention of promoting homosexuality'. It was repealed in England and Wales in September 2003 [Stonewall. *Glossary of Terms*. Stonewall; 2021. URL: www.stonewall.org.uk/help-advice/faqs-and-glossary/glossary-terms (accessed January 2022)].

Tanner stage Describes scale of measuring stages of puberty according to physical development and development of primary and secondary sex characteristics. First identified by paediatrician Professor James Tanner.

Tavi Tavistock and Portman National Health Service Trust. Home to Gender Identity Development Service and London Gender Identity Clinic.

Top surgery A way of referring to surgery that involves breast tissue removal and chest contouring, and/or breast implants.

Trans An umbrella term to describe people whose gender is not the same as, or does not sit comfortably with, the sex they were assigned at birth. Trans people may describe themselves using one or more of a wide variety of terms, including (but not limited to) transgender, transsexual, genderqueer, genderfluid, non-binary, agender, two-spirit, bi-gender, trans man, trans woman, transmasculine and transfeminine.

Trans affirmative Affirming the validity of a trans identity.

Transfeminine Transfem/transfemme, fem/femme. Usually describes people assigned male at birth (AMAB) whose gender identity is partially or fully feminine or aligns with femininity.

Trans inclusive Providing a supportive, accessible and non-discriminatory environment for trans and gender-diverse people. Promoting and protecting the rights of trans people and meeting their needs.

Transition The term used to describe the process which someone goes through to live as a different gender from the gender that was ascribed to them at birth.

Trans man/male A term used to describe someone who is assigned female at birth but identifies as male and lives as a man. This may be shortened to trans man, or FTM, an abbreviation for female to male.

Transmasculine Transmasc, masc. Usually describes people assigned female at birth whose gender identity is partially or fully masculine or aligns with masculinity.

Trans woman/female A term used to describe someone who is assigned male at birth but identifies as female and lives as a woman. This may be shortened to trans woman, or MTF, an abbreviation for male to female.

Two-spirit A sacred and historical identity. A term created by and for Native American/First Nation and indigenous people. Can be used to refer to gender identities that are outside the binary or a 'third gender'. Can refer to an indigenous/First Nation person who identifies as having both a masculine and a feminine spirit.

List of abbreviations

Ace	asexual
AFAB	assigned female at birth
AMAB	assigned male at birth
ASD	autism spectrum disorder
CAMHS	Child and Adolescent Mental Health Service
CLAHRC	Collaboration for Leadership in Applied Health Research
DSM	Diagnostic and Statistical Manual of Mental Disorders
GIC	Gender Identity Clinic
GIDS	Gender Identity Development Service
GIRES	Gender Identity Research and Education Society
GP	general practitioner
HRT	hormone replacement therapy
ICD	International Statistical Classification of Diseases and Related Health Problems
LGBT	lesbian, gay, bisexual, trans
LGBTQI	lesbian, gay, bisexual, trans, queer, intersex
NHS	National Health Service
PCOS	polycystic ovary syndrome
PPI	patient and public involvement
ROGD	rapid-onset gender dysphoria
SSC	Study Steering Committee
T	Testosterone
TERF	trans-exclusionary radical feminist
TPOC	trans people of colour
WPATH	World Professional Association for Transgender Health

Plain language summary

In the United Kingdom, there is a lot of debate and misleading information about young transgender people's access to health care. Transgender young people face many challenges including being treated unfairly in healthcare services. They face long waits for specialist services and, as a result, often turn to online spaces for information and support. However, finding good-quality information can be difficult. When young people do not get the support they need, it can impact their well-being and mental health. Through interviews, we listened to young trans people talk about their experiences of health care and how they thought this had affected them. We also talked to parents/carers of young trans people and people who work in health care to better understand their experiences.

Doctors and people who work in health care also spoke about not feeling supported. They felt they needed better information and training. Young people wanted to reach a shared agreement with doctors, rather than doctors deciding if and when treatment should happen. They wanted doctors to know more about supportive care for transgender young people, and to appreciate that there are many ways to be transgender. Parents experienced difficulties too. They felt they did not get much support when their child was on the waiting list, and thought the assessment process was unclear. Many participants talked about negative attitudes and unfair treatment of trans people in health care. This means there is a need for improvement in health care for transgender young people and families. This includes changing the way that decisions are made to improve young people's experiences. Better training for doctors is needed, that is more supportive of young people, making sure they are listened to, respected and believed. Finally, the National Health Service needs to positively influence current debates and challenge false and misleading information about transgender people.

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.

Funding

This award was funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme (NIHR award ref: 17/51/07) and is published in full in *Health and Social Care Delivery Research*; Vol. 13, No. 4. See the NIHR Funding and Awards website for further award information.

Chapter 1 Introduction and context to the study

Introduction

At the time of writing this report, trans people in the UK continue to be subject to a 'culture war debate'.[1] Arguments about gender identity have become increasingly polarised in public discourse and political discussions. At the core of this debate is an ideological dispute around what gender means, with divergent ontological understandings of the categories of 'sex' and 'gender' and conflicting understandings of their relationship.[2] For some, there is the view that change(s) in gender identity represent a threat associated with a breakdown in the established social and moral order, leading to presumed anarchy and chaos in public bathrooms, competitive sport and childhood. Reductive and essentialist readings of sex have notably re-emerged within these debates, with calls for more regulation and policing, often of trans women.[2] More widely, cisnormative (or trans-exclusive) logics of sex and gender presuppose and assume fixidity.[3] On the other hand, much historical and contemporary feminist thought on sex variation and natural gender diversity has shown that attempts to strictly define and police sexed bodies are highly problematic.[2,3] Moreover, there is the view that transgender people have the human right to live, and any serious commitment to improve the social and material conditions for trans people (as with any minority group) could *actually* be a marker for modernity and progress benefitting all.

Crucial to any critical health research on gender diversity is locating it in contemporary trends and current pervasive cultural norms, not least because (research) questions about gender are inseparable from the politics of gender. Gender differences and diversity exist within and through our body's relations with the world.[3] That is, the act of transitioning is much more than realising a pregiven, internal truth but a requirement for a change in and a reflection on society and how our milieu operates.[3,4] This reflection is pertinent when there is an aim to foster equitable and just conditions in health care for trans people.

In the UK, trans young people have been caught up in the centre of a number of devastating political storms and debates. The growth of anti-trans sentiments fuelled by opinion groups have influenced high-profile discussions and policy decisions about the appropriateness of medical interventions, including puberty suppressant treatment.[5] Hostile coverage has also led to delays in proposed reforms of the Gender Recognition Act, including legal recognition for under-18s and the decision to exclude trans people in the conversion therapy ban.[5] Compounding this, trans young people face lengthy waiting lists when seeking gender identity services, with delays and problems with the referral process.[6–10] The lack of access to appropriate health care has had a profound impact on young trans people. Trans young people experience higher rates of psychological and social difficulties resulting (in)directly from prejudice and discrimination, gender dysphoria and social pressures.[11]

Facing multiple challenges and different forms of marginalisation in health care, employment and housing, trans people of colour (TPOC), those with disabilities and those on low incomes are at the sharp end.[12] The COVID-19 pandemic further exacerbated these pressures and existing divisions. More widely, it has been reported that, since 2020, hate crimes in the UK (particularly those that are racially motivated) were at an all-time high.[13,14] Official Home Office figures revealed that the number of hate crime against transgender people reported to the police had more than doubled in the past 6 years (2016–21).[15] Stonewall suggested that the figure could be much higher to account for unreported hate crimes.[16]

What has emerged in recent years is a persistent public discourse, particularly in the media, which constructs polarised accounts of trans people's lives, identities and healthcare needs. One of the consequences of such social polarisation in contemporary UK society is that it places trans people in a contradictory space – one which both celebrates visibility and diversity while denigrating trans existence. We have witnessed some organisations declare their support for transgender staff, yet decry and leave well-established lesbian, gay, bisexual, trans+ (LGBT+) diversity schemes. These contradictions continue:

> *Trans people in [the] media are exceptionalised either as tragic voiceless victims (suicide stats) as reactionary figureheads, or as platitude spouting celebrities platformed to solidify ideas of what a trans person is (trans influencers who rarely talk about material conditions beyond pronouns).*[17]

Such depictions are not coincidental: questions about our identity and symbolic issues in society reveal a set of further desires – around reinstating and reinforcing (gender) binaries.[2] Constructing and reproducing a polarity against otherness or difference becomes an anticipated reaction to groups or communities that are perceived to transgress racial, sexual or gender norms and threaten the status quo. Averett, in her research on online news comments, suggests that for some people, their ontological anxieties (questions about what exists) of trans bodies means that they will use online spaces to re-establish binaries of race, gender and age as a way of dealing with this issue.[18] The role of social media has become influential, and whether such platforms reproduce polarised social worlds in the virtual is much debated.[19] Many trans youth have found online spaces providing community, connection and shared belonging, as well as vital information and support.[20,21] At the same time, existing hierarchies and social structures can be magnified. Privileged and powerful people have claimed to be silenced or had their views about trans people 'cancelled', while the very marginalised groups that such people claim silence them, like trans young people, are given little space in wider discourses to counter such assertions.[1]

One reason why discrimination against transgender people appears to have gained some traction is because of a reactionary politics that has found a 'respectable' front. This has been noted by others who suggest that trans-exclusionary white feminists create media outrage through, for example, constructing trans women as dangerous to 'repackage trans equality itself as predation'.[22] As the journalist Jacobson notes, prominent figures attempt to provide a 'slow transfusion of bigotry … in the national consciousness'.[23] It is argued that transphobia in its contemporary form is predominantly 'a sense-making process of gender for and by the upper middle classes' and in this way has become gentrified.[12] Similarly Norris suggests that right-wing scholars in predominantly liberal social cultures are most likely to perceive that they faced hostility, despite their silencing claims being 'rhetorical dog whistles devoid of substantive meaning'.[24]

Notwithstanding, arguments about 'silencing' and free speech have largely become a smoke screen for the very real material conditions that (young) trans people live with. This project takes an intersectional approach examining how health care is interlinked to people's housing, employment and social conditions including their emotional health and well-being. The research has been carried out against a backdrop of evidence of repeated and systematic failings in health care for trans people. It charts every day, non-extraordinary and mundane aspects of trans peoples' lives – many of which represent constant struggles though also joy and defiance. The tension and coexistence of such accounts are something that strongly permeate all our interview data.

This research project has grown within this complex milieu. Like any qualitative project, it values participants (and their narratives) through in-depth discussion and interview. More than this, it takes the struggles which trans people live with and speak about, seriously. In this, we started by asking gender-diverse people themselves about their experiences in seeking health care as well as education, employment, as well as family/relationships more generally.

We concur with other colleagues working in this area, that toxic 'debates' remain an ever-present and disturbing backdrop to trans research, exacerbated by the COVID-19 pandemic.[12] As expressed in our data from young people, a trans-hostile environment in the UK has created dangerous fearmongering and sensationalism (on issues such as puberty blockers) (see *Chapters 4* and *5* for more on this). As a mixed team of both cisgendered allies and trans academics, we have, like other researchers in this area, faced both the hostile as well as 'respectable' face of discrimination. As McKeand remarks 'no action is more despicable than that justified by those wearing the mask of rational intellect' (p. 42).[25]

The COVID-19 pandemic, contrary to calls of #bekind, appears to have intensified such discriminatory experiences. And at the same time, we witness the acts of kindness that can be found at the local neighbourhood level and within community and charity organisations to ameliorate and provide hope for trans colleagues. We therefore write here both with conviction and caution – knowing that those who want to create and spur divisions, will again seek to undermine us on blog posts, victimise our (trans) researchers on social media, and will write to our employer complaining about us doing our job.

In reflecting on these journeys, we also chart the difficulties and realities faced by those who research in this area, the very real costs for those (trans) researchers involved and explore learning points so that such 'incessant, fruitless debates [do not] sap our energy and interfere with our ability to focus on the tasks in hand' (p. 883).[12] This became one of the key challenges the research team faced as we experienced a concerted campaign to derail the research.

These pressures meant that there were staff changes in the make-up of the research team. However, changes in the team, did not compromise the fundamentals of the research both practically and intellectually. The commitment to the aims and objectives of the research were unwavering.

Trans health care

Historically, trans people have endured discrimination, pathologisation and victimisation for more than a century, although there are distinct variations by geography, culture, space and time (see Vincent and Manzano for a discussion on the different ways gender has been understood historically and spatially especially in the Global South).[1,26] In this report we primarily concentrate on the UK context, specifically England, while acknowledging the geographical variations between and within different regions, as well as urban and rural areas. We also draw on international research and guidelines which inform policy and practice globally.

There are an estimated 0.5–3% of the population who are trans, non-binary or gender fluid.[27,28] Trans and gender-diverse people frequently experience difficulties accessing suitable health care, whether specific to their gender needs or more generally (Winter *et al.* 2016).[29] Carlile suggests that healthcare services in England have not kept pace with demographic change despite UK equalities legislation.[6] What has been missing is an affirmative approach as mandated by international guidance on transgender health care designed to protect trans people from discrimination[6] see also Hidalgo *et al.* for a summary of the affirmative model).[30]

Globally, the World Professional Association for Transgender Health (WPATH) guidelines state that services should 'provide health care (or refer to knowledgeable colleagues) that affirms gender identities and expressions, including health care that reduces the distress associated with gender dysphoria (if this is present)'and that work with adolescents facilitates exploration 'openly' and 'respectfully', while children are responded to 'supportively'.[31] WPATH guidelines also make explicit the need to consider the multiple contexts for assessment of children and young people alongside the benefits and harms of different treatments [see WPATH website (www.wpath.org) for more on the *WPATH Standards of Care for the Health of Transgender and Gender-diverse People*, Version 8].

Further, international guidelines advise practitioners to treat the individual and be aware of diverse needs for different patients: what may be desired by one patient to alleviate gender dysphoria may not be needed or desired by another.[31,32] Health professionals have an important role to play in directly assessing gender dysphoria in children and adolescents, providing family counselling and supportive psychotherapy to assist children and adolescents in exploring their gender identity, and making an appropriate referral for further physical interventions.[31,32]

In the UK in 2016, the House of Commons Women and Equalities Parliamentary Select Committee report on *Transgender Equality* highlighted serious failings and poor patient experiences in health services for transgender people.[33] They identified a number of key decision-making points where health services were failing including: responses from primary care general practitioners (GPs), referrals to Gender Identity Clinics (GICs) for adults, and Gender Identity Development Services (GIDS) for children and young people, and access to hormone treatment.

The act of seeking health care as a trans person is often described as a challenging and frustrating process.[34] Research suggests that when trans and non-binary people engage with healthcare services, they encounter a lack of knowledge by healthcare professionals which often leads to trans people having to provide education and information.[35] In this way, trans people often bear the burden of having to fill in the gap in knowledge and lack of training for healthcare professionals.[36,37]

As Zhang suggests, 'a climate of transphobia, a stretched NHS and an archaic infrastructure that pathologises inflexible pathways' has contributed to an increasingly desperate situation for trans and non-binary people seeking healthcare treatment.[38] Research indicates that TPOC are often at the sharpest end of this, experiencing a multitude of prejudices and negative reactions to their race/ethnicity and/or gender identity when seeking health care.[39,40]

Trans peoples' poorer health outcomes have been amplified by the COVID-19 crisis, as gender services have been deprioritised, resulting in longer waiting lists, cancellations and delays for appointments and treatment.[12] These effects are compounded by trans people experiencing higher levels of unemployment, and precarious and low-paid employment as well as housing insecurity.[12,29,41]

It has been suggested that conservatism in primary care often complicates and delays access to treatment for trans people, particularly concerning hormone therapy.[42] Furthermore, attempts to gain access to appropriate treatment via primary care GPs are fraught with significant financial, discriminatory and knowledge barriers.[43] Barrett advocates the need for a joint care model for trans people whereby primary care, GIC practitioners and specialists work together to ensure timely hormone prescriptions informed by best treatment protocol.[43]

Reisner *et al.* discuss the informed consent model and advocate a shift away from pathologisation.[44,45] Trans people have long been calling for an informed consent model that centres the patient's healthcare needs flexibly without gatekeeping treatments based on professional assumptions and views about identity.[46,47] The informed consent model removes unnecessary barriers to hormone therapy, including restrictions specifying prolonged mental health evaluations and tests (i.e. living fulltime in one's self-identified gender) to obtain hormone therapy that had long been embedded in existing standards of care.[44,45]

Calls for de-medicalising healthcare processes and moving closer to a system of self-declaration have also long been proposed by the trans community. Previous and successive UK governments had committed to reforms of the Gender Recognition Act 2004 that would allow trans and non-binary people to self-identify without having to endure lengthy medical assessments that are frequently experienced as 'intrusive, inaccessible, daunting and expensive' (p. 838).[48] Long-standing overdue changes and reforms are frequently caught up in public debate.

The growth of anti-trans sentiments has taken its lead from determined US-based lobby groups to undermine changes to the Gender Recognition Act.[5] It is worth noting that in the USA the first 2 months of 2023 saw 150 bills (proposed legislation) specifically targeting the rights of transgender people.[49] Taiwo Owetami, MP for Coventry, North West, in the UK, then , then Shadow Minister for Equalities, suggested that lobby groups actively

> *oppose LGBT+ inclusive education, believe that adolescents should not be able to access puberty blockers (in flagrant disregard of the entire concept of "Gillick" competency), criticise measures to make conversation therapy illegal, [and] reject the very existence of non-binary people, [while refusing] to condemn as homophobic those who would deny same-sex couples the right to marry.*[50]

The Chair of the Women and Equalities Committee 2021, part of the House of Commons review of the Gender Recognition Act, stated that the Act was 'crying out for modernisation'.[51]

Health care for trans young people

It is well established that trans and non-binary young people have poorer access to health care with higher rates of psychological and social difficulties. These problems have been found to result directly and indirectly from gender dysphoria, social pressures around hiding oneself, and experiencing prejudice and discrimination.[11] Young people can be more vulnerable as they can have additional stressors such as limited financial resources and often rely on parental support.[52,53] There is growing evidence around parental support, which shows that strongly supported young people are only slightly more anxious than cisgender young people, and experience fewer mental health issues including less suicidal ideation.[54,55] Gender-affirming medical therapy and supported social transition can lead to improved psychological functioning for trans and gender-diverse young people.[56]

Before the pandemic, the only NHS-funded service for gender-diverse young people in England and Wales (the GIDS at the Tavistock and Portman NHS Foundation Trust) had seen a large increase in referrals over several years. Long waiting times are well documented and are shown to adversely affect trans-identified people's mental health.[57] This has related to anxiety, sleeping problems and distress.[58] With the pandemic, long waiting lists have been amplified by an already overstretched NHS – many young people are experiencing cancelled appointments, delayed treatment and difficulties getting prescriptions for hormones.[12]

Young trans people have been caught up in political storms, most notably regarding access to puberty suppression treatment. In December 2020, the High Court ruled that transgender adolescents could no longer start medical gender-affirming treatment below the age of 16 years unless a court order was obtained (High Court, *Bell vs. Tavistock*, 2020 EWHC 3274). This had significant consequences for trans young people and resulted in a legal challenge around best interests, harm, consent and Gillick competence.[59] In September 2021 an appeal won by a coalition of the Good Law Project alongside several charities and organisation such as Gendered Intelligence reversed the original judgement.

In 2021, NHS England and NHS Improvement commissioned an independent review of Gender Identity Services for children and young people. The report was published in July 2022 and led to the decision to close the GIDS for children and adolescents, which was deemed 'not a safe or viable long-term option' for trans young people. The GIDS will be replaced by two regional centres: one in London and another in the North West, followed by other regional sites of a total of up to eight (see *Chapter 10* where we discuss this issue further).

Resources and information

To cope and thrive against a backdrop of such challenges, it is no surprise that online resources and spaces have become increasingly important for trans young people.[60] Gender-diverse young people and their parents are likely to access information through a range of online sources adopting diverse, creative and critical digital strategies for both self-expression and community formation.[6,60] It has been found that young people seek information and support on a range of issues; for example, to help explore their identity and gender expression, decisions about transitioning, medical interventions and implications for family relationships, employment and broader social stigma.[29] Social media can be both a resource and a path to self and authenticity.[61]

A Stonewall report highlighted the importance of access to good-quality resources and information to ensure a young person's well-being, safety and happiness.[62] However, the reality is that young people may be exposed to misinformation and lack of support. The consequences of not being able to access information can lead to further isolation, mental health problems and detrimental impacts on attainment, particularly in education (Ibid).

Finding support and information at school and home is far from straightforward: approximately half of trans-identified young people have not told their parents or siblings they are trans, and 28% have not told anybody, including school staff and peers.[63] Almost two in three trans-identified pupils report being bullied for being LGBT+ at school, one in ten receive death threats and more than two in five have tried to take their own lives.[62] Compounding this, only one in three LGBT+ pupils say that their school provides information on LGBT+ topics and relevant signposting to resources and organisations, and only one in four say that their school tells them where they can access information online about LGBT+ issues. Such LGBT education may not even include trans-specific education either or signpost where it can be found (this was prior to new guidance on sex education issued by the UK government in 2024).

It is therefore important to direct young people to supportive and current websites with relevant information, so that they are able to make informed choices.[63] The research has addressed this particular problem with the aim of providing young people and families with up-to-date information on the lived experiences of being gender diverse on a well-established and reputable website called Healthtalk.org.

Many young people are on the waiting list for gender specialist services and therefore might need a supportive website to consult. It is known from previous research and Healthtalk.org studies that seeing and understanding others' experiences can contribute to feeling less alone and better prepared and informed in what a person is facing.[64]

Our co-applicants highlight how the range and diversity of gender experiences and expressions are not always easy to find in resources and information, despite expressions of gender online showing considerable variation and diversity.[65] Therefore, there is a need to have greater representation of the diversity of gender experiences and expressions in resources and information – with research that is sensitive to multiple identities and subjectivities.

Parent and family support

Providing support to families including parents and carers is important because the reactions and behaviour of a gender-diverse person's parents and family members can be critical.[66]

Parents' and carers' support and acceptance are fundamental for the well-being and mental health of young trans and gender-diverse people.[67,68] Lack of family support is linked to adverse life outcomes and poorer mental health in young trans and gender-diverse people.[67,69] Parents and carers are often key in facilitating and 'managing' healthcare processes and appointments for their young person. Parents and carers who affirm and support their young trans or gender-diverse person often act as advocates for them across a range of healthcare, educational and social settings.[6,70,71] Families, parents and carers are also likely to have their own questions while facing considerable 'debate' and misinformation about transgender young people. This research has therefore sought to better understand how parents/carers navigate and experience these issues and how they have experienced health services (see also Mikulak 2022[72] for analysis of this based on the parent/carer data in this project).

Aims and objectives

Aim

Our primary aim was to improve the care and support for young people and their families before and after referral to NHS gender identity services. Given the diversity of our sample, which covers a wide breadth of gender experiences, our research can provide support for young people on the waiting list, but also those who are unable to remain on the waiting list, and those who do not seek gender specialist services.

Objectives of the research

- Develop a holistic 360-degree understanding of the perspectives and experiences of young people, families (parents/carers) and 'gateway' professionals who care for gender-diverse patients.
- Identify ways in which NHS services, particularly specialist gender identity services, can be improved and develop resources to help achieve these improvements.
- Support young people and their families through the development of two new sections on the Healthtalk.org website.
- Evaluate these Healthtalk sections with young people and families on the waiting list for services.

Structure of the report

This chapter has provided a background to the study and has considered the sociopolitical context in which it is set, alongside research evidence. *Chapter 2* outlines the design and methods of the study. After this we set out our community and charity partner involvement [often referred to as patient and public involvement (PPI) in health sciences], before three chapters that present the empirical findings from our parent/family data, young people collection and health professionals.

Chapter 7 presents a summary of the formative evaluation and dissemination event followed by *Chapter 8* on the project outputs and impact. Finally, *Chapters 9* and *10* summarise the main findings and consider the implications for the development of health policy and practice, providing recommendations for improving the experience of health services for trans and gender-diverse young people and their families.

Themes from the interviews with parent/carers are identified and explored further in a peer-reviewed book, which explores the love, support and everyday practices of advocacy involved in parenting trans and gender-diverse children and young people.[72]

The project was always designed to be collaborative, but where individual researchers would be able to develop their own initiatives based on either aspect of the project's data or themes under discussion within the project or both. The project sees this wider intellectual endeavour as critical to its success, especially where project members can develop ideas that the project itself could not undertake. The project is especially proud to have enabled this spin-off initiative, where the origins, and uses of project data facilitated its publication. Discussion and development of the original interview guide, emergent themes and analysis within the project have contributed to and underpinned the development of the book. The themes of advocacy and support, for example, run strongly throughout the project data from parent/carer interviews (see *Chapter 6*) and are explored in more detail in the book. Similarly, the ethos and political commitments of the wider project, as explained here in the introductory chapter, have always been rooted in improving the care and support for young trans people and their families; taking an anti-oppressive stance against misinformation, transphobia and attacks on the few hard-won rights that trans people have. These are the core values and ethics of the project – they are what we stand for. While this stance did not suit all, publications emanating from the project have all characterised the urgency of the situation for trans people.

Chapter 2 Research methodology

Introduction

Methodology indicates the choices we make about what to study, the methods to be used for gathering or generating data, and how those data are to be analysed.[73] It involves theoretical as well as methodological issues informing the choices of method made.

Despite the contested and changing nature of qualitative research, there is agreement that qualitative research goes beyond subjective ‘meaning’ towards issues of language, representation and social organisation.[73] In this research, we took a qualitative approach to gain a deeper understanding of gender-diverse young people and family experiences, to investigate their experiences of health care. Narrative interviews were chosen to allow participants to convey the stories that are meaningful to them and there is often overlap with life history, biographical and oral history interviews.[74] As such, this denotes a preference for an interpretative (focus on meanings, understandings and emotions) – rather than a more positivist – following the natural sciences approach to knowledge production. Indeed, the topics explored in Healthtalk interviews (research interviews that form the basis of sections on the Healthtalk website) are always plural (not singular) including wider social factors affecting a participant; for example their education, experiences of family, relationships, and historical events.

Literature and field review

Prior to interviews, we conducted a literature search and field review. The purpose of this was to inform recruitment and highlight issues for inclusion in the interviews. Gaining knowledge on what has been written before also guided the broader study. The search strategy for literature was developed through an iterative process with the support of a specialist librarian (Bodleian Library, University of Oxford, Oxford, UK). Search terms included keywords, synonyms and term variations (e.g. transgender young people, trans and non-binary young people health care). These were used to search a range of health and social science databases, including MEDLINE, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), EMBASE, PsycInfo® (American Psychological Association, Washington DC, USA), Education Resources Information Center and Education Database, Sociological Abstracts, and the Social Science Citation Index. Studies between 1994 and 2019 (when the literature search began) were included. This returned over 500 papers.

Papers were read independently by two experienced researchers on the team (MM and SM) and following a critical qualitative synthesis approach, analysed according to topic and relevance to trans health care. Data extraction for key themes happened independently followed by joint working. This was used to form the basis of a literature review, which summarised the key findings from previous research. The literature review was updated during the course of the project.

Qualitative interviews

Our primary method of data collection was semistructured in-depth interviews. Following our protocol,[75] over 90 qualitative interviews were conducted by two experienced qualitative researchers (MM and SM) working at the University of Oxford, with three participant groups:[75]

1. 20 health professionals working with trans patients.
2. 50 young people (42 young people aged 13–24 years and 10 young adults aged 25–35 years).
3. 19 family members of gender-diverse young people (parents/carers).

Interviews were conducted pre pandemic, starting in 2019 and continued throughout the pandemic. All health professional interviews were conducted pre pandemic, with the parent/carer and young people interviews conducted mainly face to face, with a proportion conducted online. Interviews took place in participants' homes or other place of participant's choosing; health professional interviews were conducted in their place of work and/or by phone. Alternatively, interviews were collected remotely via Microsoft Teams® (Microsoft Corporation, Redmond, WA, USA) or by telephone.

The interview schedules (see *Appendix 1*, *Appendix 2* and *Appendix 3*) for each of the three participant groups were informed by the relevant topics in the literature review and aimed to reflect a diverse, critical and comprehensive understanding of trans health care.

Two experienced qualitative researchers conducted the interviews, using a narrative approach.[76,77] This approach allows an oral history to be collected, thus allowing the participants to highlight their own concerns, values, meanings and priorities. Supplementary questions prompted reflections on issues raised in the narrative section, as well as participants' experiences of current health service provision. Any good practice/positive experiences were explored as well as challenges, specific problems and issues encountered. Participants were asked if they had messages for others starting out on the same journey and if there was anything they would like health professionals to learn from their experiences.

Conducting interviews for this research is intrinsically tied to the production of the Healthtalk.org site. Healthtalk is an award-winning website which features video, audio and written clips of people talking about their health experiences. Healthtalk.org publishes broad samples of experiences of what is important to participants.[64] Currently, there are over 100 sections on the website, with topics on mental health (e.g. depression and low mood in young people, eating disorders in young people, psychosis, mental health experiences of ethnic minorities and ethnic minority carers, parents' experiences of self-harm), sexual health (young people), chronic pain, young peoples' experiences of seeing their GP, and young peoples' experiences of long-term health conditions. Healthtalk resources are freely available and many have overlapping themes and topics; for example, the sections on mental health and sexual health are likely to have relevance for visitors to this project's resources and vice versa.

In line with other Healthtalk projects, this research followed robust and rigorous qualitative methods, well established over 20 years by the Medical Sociology and Health Experiences Research Group at the Nuffield Department of Primary Care Health Sciences, University of Oxford. The summaries (themes or topics which emerge from the data) go through a rigorous process of editing and checking (called 'buddying'), as well as systematic evaluation (see *Analysis*). Members of this team had extensive experience of previous Healthtalk interview studies with analytical methods and results published in high-impact clinical and social science journals.

Health professional interviews

Semistructured interviews, audio-recorded with consent, were conducted with a purposive sample of 20 health professionals [including those from 'gateway' services such as GP surgeries, Child and Adolescent Mental Health Service (CAMHS), GIDS and GICs]. A broad range of health professionals were recruited to the study, including GPs, practice nurses, counsellors, and mental health practitioners (see *Appendix 6* for composition of health professionals interviewed).[36] Clinicians from rural and urban settings, of different ethnicity, age and time since qualification were included. Clinicians were both cisgendered and gender diverse. Interviews explored experiences of working with gender-diverse patients, problems encountered, examples of good practice and how patients were supported in decision-making. See *Appendix 1* for the interview schedule.

The health professional interviews were transcribed verbatim by a professional transcriber, checked for accuracy and then thematically analysed by two researchers (MM and SM). Findings informed the broader project including the dissemination event, and were published.[36] In *Chapters 6* and *9* we explore these findings more thoroughly.

Interviews with young people

As explored in *Chapter 1*, few studies collect information and views from young gender-diverse people themselves, with young people often denied a meaningful voice. As Carlile *et al.* suggest, little is documented about the journeys that trans young people (and their families) go through in finding clinical care.[6]

Participants

In total, 52 interviews were conducted, with two participants not responding to consent/copyright permissions. The remaining 50 interviews were with young people and young adults aged between 13 and 35 years (as per our protocol, this comprised 42 under the age of 24 years and 10 between 25 and 35 years). Interviews were conducted face-to-face in participant's homes (n = 20) or other locations deemed suitable by the participants (n = 4). Twenty-eight were conducted online/by telephone due to the pandemic. All interviews with young people were conducted by SM. Interviews lasted between 90 and 300 minutes and were digitally audio- and/or video-recorded for transcription and analysis. The interview schedule was developed from the literature search, with assistance from the wider research team (see *Appendix 2* for complete list of questions included).

Recruitment and selection

To achieve as diverse a sample as possible within relatively short timescales we developed a range of recruitment strategies. Participants were recruited purposively and through snowballing. First, a purposive sampling technique was employed to capture a maximum variation sample.[78] As per our protocol, participants were recruited through co-applicant networks (e.g. GIDS and Gendered Intelligence), social media routes, advisory group members; local and national support groups; social and print media and snowballing.[75] This sampling frame was selected because it enabled the researchers to focus on the minority sample of trans and gender-diverse young people, that otherwise would have been difficult to access.[74]

For both the young people and parent/carer interviews, a database of potential and actual participants was maintained by the two main researchers (SM and MM) and reviewed at regular intervals with the research lead (SR) to ensure sufficient recruitment from people with diverse gender experiences, minority ethnic and socioeconomic backgrounds, as well as from a variety of different sources (i.e. not just from social media) and regions of the country (*Table 1*). In the next chapter we explore our youth panel and TPOC panel involvement in more detail.

The maximum variation sample reflected different types of experiences at different points in peoples' journeys, and socioeconomic and ethnic diversity. It included young people who identified as trans girls/women/femme, trans boys/men/masc, non-binary, gender-queer, androyne, bi-gender and/or other self-identified name. We included participants who wanted surgical/hormonal treatment, and those who did not want any physical intervention or were undecided. Participants used a range of healthcare options (NHS services/private health care/self-medication). Some participants describe their identities as fixed, whereas others had a more fluid expression of gender identity. Participants had a variety of socioeconomic backgrounds and were recruited from 26 counties across England, Wales and Scotland. Approximately 38% of our sample were from minority ethnic groups. Researchers working with trans and gender-diverse young people report an over-representation of white, middle-class participants.[79,80] It was important to apply an intersectional lens to the experiences of health care which meant improving the diversity beyond 90% white samples in previous LGBTQ+ research.[81]

Although the study was exploratory rather than definitive, several factors enhanced the validity of the findings. In particular, the comprehensive sample size; breadth and range of participants, including some

TABLE 1 Demographic information (young people sample)

Participant characteristics	
Demographic information	**Demographic information**
Age, mean (SD)	22.98 (5.30)
***Gender*, *n* (%)**	
Male	21 (42)
Female	15 (30)
Trans femme	1 (2)
Trans masculine	2 (4)
Non-binary	8 (16)
Agender	1 (2)
Genderqueer	2 (4)
***Ethnicity*, *n* (%)**	
White	*31 (62)*
White English	28 (56)
White Welsh	3 (6)
Asian	*6 (12)*
Pakistani	2 (4)
Indian	2 (4)
Chinese	2 (4)
Black	*5 (10)*
Black African	2 (4)
Black Caribbean	2 (4)
Mixed Black Caribbean	1 (2)
Mixed	*8 (16)*
Mixed White Asian	4 (8)
Mixed White Caribbean	3 (6)
Mixed other	1 (2)
***Region*, *n* (%)**	
London	9 (18)
East	1 (2)
South East	6 (12)
East Midlands	5 (10)
West Midlands	9 (18)
North West	4 (8)
North East	1 (2)
Yorkshire and Humber	5 (10)
Wales	4 (8)
Scotland	2 (4)

TABLE 1 Demographic information (young people sample) (*continued*)

Participant characteristics	
Demographic information	**Demographic information**
***Sexuality*, *n* (%)**	
Straight/heterosexual	7 (14)
Gay	4 (8)
Lesbian	2 (4)
Bisexual	12 (24)
Pansexual	7 (14)
Asexual	3 (6)
Questioning	5 (10)
Queer	7 (14)
Not disclosed	3 (6)

participants that could be defined as outliers; the in-depth nature of the interview process; the rich descriptions by participants of experiences of services; the checking of findings and validation by other research team members and external sources (including triangulating the data from both researchers); the sharing of findings with participants (to achieve a degree of respondent validation); and the constant comparison of the data. All procedures were accurately documented and re-examined at every stage of the research.

Parent/carer interviews

Qualitative semistructured in-depth interviews were conducted to explore the experiences and support needs of parents and carers of young trans and gender-diverse young people.

Twenty-two parents and carers of young trans and gender-diverse people were interviewed. The total number of interviews conducted was 20, with 2 interviews conducted with couples. One participant withdrew and two were not contactable after interview; thus the data collected is based on the remaining 19 participants. Participants were selected purposively to cover different age groups of young people and a wide range of experiences with health care (primary, mental health and specialist gender identity services). Participants were recruited through a variety of channels in the same way as the young peoples' interviews as above.

The interviews were conducted face-to-face in people's homes (n = 12) or other locations deemed suitable by the participants (n = 5), over the telephone (n = 1) and via Skype® (Microsoft Corporation, Redmond, WA, USA) (n = 1). All interviews were conducted by MM. Interviews lasted between 45 and 140 minutes and were digitally audio- and/or video-recorded for transcription and analysis. The interview schedule was developed from the literature search, with assistance from the wider research team (see *Appendix 3* for complete list of questions included). The aim was to holistically map out and understand experiences of parents and carers and how these are shaped by (1) systemic conditions (e.g. the existing healthcare pathway for young trans and gender-diverse people) and (2) parents and carers' strategies in supporting their young person and themselves.

As per our protocol,[75] we did not seek to interview matched pairs of young people and family members (parents/carers). This was to ensure safe recruitment for young people – some young people did not have good relationships with their parents and pairing interviews would have excluded this cohort. Of the parent sample, 5 men and 14 women were interviewed. Sixteen participants were biological parents of a young trans or gender-diverse person, one participant was a step-parent, one was an adoptive parent and one was a foster carer. Parents all identified as cisgender. The interviewees were parents and carers of young trans and gender-diverse people aged from 9 to 25 years of age. The age breakdown for the young people whose parents and carers were interviewed was as follows:

- 9–10 years old – 2 young people
- 11–13 years old – 4 young people
- 14–16 years old – 6 young people
- 17–19 years old – 4 young people
- 20–25 years old – 3 young people

From the 19 young people whose parents and carers were interviewed, 10 were trans feminine, 8 were trans masculine and 1 identified as non-binary.

Analysis

The narrative interviews for both the young people and parent/carer 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, sent to the interview participant for checking and copyright assigned to the University of Oxford.

Analysis was conducted using NVivo, versions 11 and 12 (QSR International, Warrington, UK) to code different aspects of people's accounts and to group similar themes (thematic analysis) across all the interviews using a modified grounded theory framework. The two central features of grounded theory are the development of theory and that it is an iterative or recursive process with data collection and analysis proceeding in tandem.[73,74] Given there is much variation in the use of grounded theory, we took a modified approach based on the accessible core principles set out by Timonen *et al.*[82] Recurrent themes and subthemes were thus identified as they emerged from the data and the method of constant comparison was used to ensure that the main perspectives on the issues that are important to participants were included.[83]

Preparation for presentation on the website

The data from the young people interviews and, separately, data from the parent/carers' interviews, formed the basis of two new online resources for publication on Healthtalk.org. For both data sets, over 30 accessible 'topic' summaries were produced, each illustrated with video/animation, audio/actor's voice or text only extracts from the interviews (approximately 250–300 clips per resource). The thematic analyses from NVivo of the data generated 34 key topic areas that informed the final topic summaries. Detailed coding reports of each topic area were made that were checked by a second experienced qualitative researcher, before writing the summaries. Draft summaries were rigorously reviewed and edited, firstly by one to two buddies, then by the principal investigator of the project, and finally by one to three members of the advisory group including consulting a medically qualified member for any medical information where appropriate. Brief biographies of the study participants were included to add context to the individual extracts from each interview. Videos and audio clips were professionally edited. The summaries and draft website content were then evaluated (see below). Final checks after this were carried out by the senior research lead (SR) on the project, the principal investigator (MS) and the DIPEx charity web team (JK) before final publication on the website. Some material in this report has been adapted from the Healthtalk.org website.

Formative evaluation

To assess the acceptability and usefulness of the two new resources before going live, we sought feedback from young people (with experience of being on the waiting list) and families through facilitated, online focus groups. We ran 6 focus group sessions over a 2-week period, with up to 8 participants in each session, with a total of 19 participants. To ensure careful recruitment within the transgender community (and to protect participants from trans hostility/harassment) while ensuring a degree of independence we recruited participants through contacts and networks of: (1) participants of the main study, (2) the young people and TPOC panels, and (3) closed online spaces/networks. We asked contacts to snowball/refer for us (i.e. participant X refers us to person Y who referred us to person Z).

Participants were aged from 15 to 69 years, from diverse ethnicities, backgrounds and geographies. They comprised young self-identified transgender people (n = 13) and related family members, including one grandparent and four parents (one trans parent and three cisgendered parents) and included one young person who had recently detransitioned. Some young people who participated in the evaluation were neurodivergent and/or had different accessibility needs. Links to the new resources were sent to participants 48 hours in advance of their designated focus group.

Each focus group session was run by MS and SM jointly. Sessions began by setting out introductions and guidelines (including information on safeguarding and participant data). The discussion was prompted by: (1) a quick recap of the website, and (2) a series of questions around website design and layout, topics and content, representation, general content and accessibility (see *Appendix 4* for the evaluation question schedule).

Feedback was collated and the online support resources revised in line with specific feedback (see *Chapter 7*). As set out in the protocol and based on a suggestion from feedback on our application from National Institute for Health and Care Research (NIHR) reviewers, we ran a prize draw (£100 Amazon vouchers) to encourage young people to take part in the evaluation (see *Chapter 7* for the results of the formative evaluation).[75]

In addition, as part of an ongoing process of updating and modification, questions from part two of an e-health impact questionnaire helped shape a feedback form located on the introduction pages of both new resources to generate additional feedback.[84] This part of the e-health questionnaire comprises 26 items that ask about views of the target health website. While the full questionnaire was too lengthy and lacked flexibility for open-ended answers, it informed some questions used in the feedback form. Ongoing feedback will be reviewed periodically by the DIPEx charity/team and are not reported here.

Research committees and ethics

The research was overseen and advised by two main panels – a Study Steering Committee (SSC) and an advisory group. The SSC met six times (members were drawn from academia, community organisations and CAMHS) and the Advisory Group met four times. The advisory group comprised academics, health professionals, parents of trans and gender-diverse young people, and charity and community organisations (Mermaids, the Proud Trust, Gender Identity Research and Education Society, DIPEx charity, and Gendered Intelligence). A separate youth panel fed into the main advisory group and also informed the research team. As above, this included two TPOC panels convened and facilitated by TPOC youth members (see *Chapter 3*).

The study is linked to the Healthtalk programme of studies and has ethical approval (National Research Ethic Services Committee for South Central Berkshire Research Ethics Committee reference 12/SC/0495) which covers an ongoing series of studies that use the same qualitative research methods to collect narratives of health issues and use the website Healthtalk.org as a primary dissemination route.

Several additional steps were taken ethically to ensure data security, confidentiality and informed consent due to the (trans hostile) climate within which this research operated. Additional discussions were had, together with further resourcing to ensure secure data storage methods, removal of identifier components, biographical detail amendments and pseudonyms. Prior to publication of the resources online, information was given to participants to ensure clear understandings of how they could change the information displayed on the Healthtalk website.

In the next chapter, we explore our engagement with charity and community partners/organisations in more depth. In *Chapters 4*–*6*, we detail the results from the in-depth interviews with young people, parents/carers and health professionals.

Chapter 3 Community and charity partners (patient and public involvement)

Introduction

We sought to consult and involve our charity and community partners through the full cycle of the research, proposal development, the active phase of fieldwork and analysis and to guide the development and coproduction of the Healthtalk resources and other dissemination activities. We were guided in particular through our networks of several charities, specifically the Proud Trust, Gendered Intelligence, Mermaids, Your True Gender (a group dedicated to helping people transition) and the Gender Identity Research and Education Society (GIRES). For a full list of our collaborators please see https://healthtalk.org/experiences/experiences-trans-and-gender-diverse-young-people/who-made-this-resource-trans-and-gender-diverse-young-people/ and https://healthtalk.org/experiences/experiences-parents-and-carers-young-trans-and-gender-diverse-people/who-made-this-resource-parents-and-carers-trans-and-gender-diverse-young-people/.

Proposal development

This project was developed in direct response to the NIHR commissioned 17/51 Gender Identity Health Services call. The topic was referred to the NIHR by the NHSE Clinical Reference Group for (adult) Gender Identity Services, to seek evidence for improvement of service provision of specialised commissioned services and of shared care with generalist services to meet escalating demand. The call identified priority topics including ‘primary research on how to improve the experience of health services for gender questioning people’ addressing how ‘children, young people and adults with gender-diverse identities navigate and experience health services, particularly “gateway” services such as GPs and CAMHS, GID/Cs, and how can this be improved?’ (NIHR 17/51 Commissioning Brief, 2017).

This research project was one of three projects awarded NIHR funding to improve the care and support for young people and their families before and after referral to specialist gender identity services.

Our response to the call by NIHR HS&DR for proposals to address this was driven by conversations with our co-applicants, trans young people on the waiting list and charity partners.

In the early stages of the proposal, collaborators provided expert insight on early ideas and drafts. This included help with the initial outline and development of the proposal and the idea of a Healthtalk module. Our collaborators highlighted the challenges facing trans young people and the mental health support needed particularly when young people are waiting for health care. They also gave feedback on how the Healthtalk resources might be used to train health professionals and used in schools. Our co-applicants talked about the need for wider cultural changes to gender norms and binaries, with a move towards celebrating (gender) diversity. Young people told us about the lack of information and support they experienced. In the initial stages, organisations such as GIRES expressed a keen interest to be involved in the project. They signposted us to helpful research on gender variance, and e-learning modules on caring for gender non-conforming people which informed our proposal further. As the proposal developed, we engaged further with our partners to form our team and start setting up an advisory group (see below). We also set up a study Facebook (Facebook, Inc., Menlo Park, CA, USA) group to start generating ongoing engagement with trans people, in particular young people.

Community partners throughout the study

Throughout the study we were guided by four groups.

Advisory group

Membership was composed of a range of representatives (For a full list of our collaborators please see https://healthtalk.org/experiences/experiences-trans-and-gender-diverse-young-people/who-made-this-resource-trans-and-gender-diverse-young-people/ and https://healthtalk.org/experiences/experiences-parents-and-carers-young-trans-and-gender-diverse-people/who-made-this-resource-parents-and-carers-trans-and-gender-diverse-young-people/). Clinical perspectives were provided by RM (general practice). Members were recruited by direct approach at chief executive/director level and built on relationships fostered during proposal development. Meetings were chaired by the project principal investigator and attended by representatives of the study team.

The terms of reference issued at the first meeting described the role of the advisory group in line with other Healthtalk.org studies. Broadly speaking, the role of the panel was to provide advice to the researchers throughout the project, help to ensure that an appropriate and diverse range of people were interviewed, provide assistance with recruitment, help ensure that all of the main perspectives were included in the web resources, and to review the lay summaries to be published on the website to ensure that the resources are sensitive, clinically accurate and accessible to a lay audience (two to five summaries per member per resource, selected according to the person's area of expertise). Advisory group input was particularly useful for both resources where summaries were reviewed multiple times by some PPI advisory group members. We also valued promotion of the project via member's own networks which aided participant recruitment. Meetings were held at regular intervals throughout the project, with agendas usually including an update and/or presentation about the research progress, including short video excerpts from interviews conducted so far. After this, meetings had significant time for full exploration and questions/discussion. Additional meetings were convened to discuss any issues arising on the project, as per NIHR protocol.

Young people's advisory panel

A young people's panel comprising eight individuals (three trans masculine young people, one non-binary young person and three trans feminine young people and one detransitioned young person) with experience of gender identity services, GPs and CAMHS were recruited via our charity partners and co-applicant networks. The group formed during the early stages of the project with some young people involved in recruitment for the two main researchers on the team. One trans young person helped the principal investigator to conduct a mock role play for candidates which involved them scoring the candidates on empathy, skill and ability to interview. This was a crucial part of the selection process to test a candidate's sensitivity, rapport building and qualitative interviewing skills.

The young people panel met once at the start of the study where, after some activities, they commented on the interview topic guides and advised on participant recruitment strategies, as well as provided insightful comment on what they would like to see in the final resource. They also helped to publicise the study within their own networks. Comments and opinions were fed back to the main panel via the researchers or other advocates from the main panel.

Owing to the difficulty in convening a meeting around school schedules and later due to the COVID-19 pandemic, subsequent input was provided via e-mail or through smaller online meetings, with opportunities for feedback arranged when specific issues arose.

Trans people of colour panels

Given that trans and queer people of colour experience further multiple barriers, we set up two trans youth TPOC panels during the study. We sought to better understand the issues facing TPOC youth by establishing two panels led by two young TPOC who acted as informants as well as participatory co-researchers. Recruitment for leading these panels was through our original young people panel networks and social media. The two lead co-researchers worked with SM to ensure that ethnic minority trans young people had a space to share experiences, first in an informal way, and second more formally as an interview participant (though this was not a requirement of the panel). Members discussed issues around trans health care generally, racism and white privilege and specific factors relating to faith, race, class and disability. There were also discussions around poverty and finance, access to health care, appointment waiting times, self-medication and prejudice. The key points raised helped shape the final resource for young people. The two researchers and participants on the panel were paid as professional members of the panels, with a high regard for their healthcare expertise and insight. Additional support was given to the main researcher and two TPOC representative researchers to work together, which involved invested time, planning and resources. The development of a relationship between the main researcher on the team and the two participatory co-researchers took place over several months. This included mainly active listening, understanding and learning from the TPOC panel expertise, as well as reading additional material and proactively better familiarising ourselves with the diverse and multiple issues facing TPOC, as well as additional layers of minority stress. We explore the findings from this further in *Chapter 4* (see *Racial inequalities and health care*).

Study Steering Committee

The SSC met six times, with members drawn from academia, community organisations and CAMHS. The SSC composition and conduct followed NIHR Research Governance Guidelines as set out in the NIHR research governance guidelines (www.nihr.ac.uk/documents/research-governance-guidelines/12154; accessed 29 November 2018). It was chaired by an experienced social science professor. Meetings were attended by representatives of the study team including the principal investigator and main researcher(s). The SSC played a vital role in providing critical comment on the study findings and contributed to discussions on specific agenda items. The SSC also provided valuable guidance for the project team when any issues and challenges arose on the project.

Key impacts of panels/groups

In discussion with the advisory group, and given the political climate for trans people currently, there was concern about participant video clips on the Healthtalk resources and that more choices should be available to participants. The groups were supportive of expanding plans to use actors or animations to give participant additional choices for how they appeared in their clips while not losing the multimedia nature of the resources.

The advisory group was also keen to ensure the diversity of the sample. They supported the research team by suggesting recruitment routes and offered practical advice for the TPOC panel involvement. The group also discussed with the research team what the content and tone of the summaries on the Healthtalk website and how to make them more accessible.

Chapter 4 Findings from the young peoples' interviews

Diversity and healthcare inequalities

Participants talked about the rich diversity in theirs and other trans people's lives, bodies and healthcare experiences. Young people wanted to see the diverse needs of trans people acknowledged and met within the current healthcare system in England and Wales. An understanding and competence of this diversity was seen as a way of addressing health inequalities for trans people. Marginalised groups within the trans community, such as black and ethnic minority trans young people, face many additional barriers to getting the treatment they needed (see *Racial inequalities and health care*).

Diverse bodies, journeys and pathways

Participants were keen to emphasise that there is no one singular healthcare pathway that denotes a 'typical' trans journey through gender identity services. They felt that NHS services fail to reflect or acknowledge this diversity in their services. Participants talked about identifying they were trans or gender diverse in many different ways. Some identified feelings of gender incongruence from a very early age, while some had feelings brought on by pubertal changes, and others recognised feelings as adults. Participants felt that the current structure of NHS gender identity services reinforced one specific psychological pathway and conceptualisation of gender development.

Dispelling myths of being 'born in the wrong body'

Part of this, was dispelling outdated narratives of transgender identities and developing an appreciation for diverse trans experiences:

> *The kind of like more classical trans narratives, you know, with the whole 'born in the wrong body' crap. I do think that like there's, it's really exciting/good to see this like proliferation of, a multiplicity of trans narratives, particularly around like non-binary and gender queer, to be non-binary specifically, yeah. I think there's something about the like demand to narrate trans in a certain way which is like not necessarily helpful.*
>
> *Diya*

> *There isn't one way to be trans. There isn't one trans narrative that we all need to fit. You know I guess the dominating one that you hear all the time is always trapped in the wrong body, knew since I was a kid, always known I've wanted to be this. You know it's just so different to a lot of people's experiences.*
>
> *Oakley*

> *I think there's definitely expectations on trans people. I think people expect you to have known from the second that you were born which I definitely didn't. I grew up with three sisters and so for me I was just as happy to play with girl's toys and boy's toys. It didn't matter to me. But people I think have this idea that from birth you have to know what your gender is. If you express anything otherwise, it confuses people.*
>
> *Kyle*

> *I wasn't born in the wrong body, I was born in my body. I just am not comfortable with certain aspects of it.*
>
> *Darby*

Many participants talked about a 'dominating' narrative often described as 'born in the wrong body'. This depicts a dominant narrative in transgender literature of early experiences of gender nonconformity, usually in childhood.[85] It has received much criticism in the literature from feminist, queer and trans theorists, who advocate for a richer and more varied understanding of trans identities.[86] Participants advocated instead for 'a multiplicity of trans narratives', inclusive of non-binary and genderqueer experiences. Participants of colour also described this as a very Western narrative that did not appreciate ethnic minority diversity.

> *I think it's really important that there's more education about it, because you know it's a very Western narrative, the idea of [being] born in the wrong body. Whereas you have, you know other countries, other cultures, other traditions, other stories indigenous people, these, these tales that have been passed down through generations, and when you see these, this, this narratives they've got, these stories they've got the attitude towards gender is a lot more relaxed.*
>
> *Darby*

Participants suggested that NHS healthcare services are not structured in such a way to appreciate cultural differences and the detailed history of ethnic minority transgender lives.

Multiple trans journeys

Participants celebrated diverse transgender journeys and felt that it was important to validate all types of pathways.

> *I mean it would be easier to say that everyone's journey is the same, I don't think they are, that's not true.*
>
> *Otis*

> *[It's] something that I think about in a more critical way. And I've come to appreciate kind of as time as gone on that there are lots of people that, that transition differently.*
>
> *Ted*

> *I'm content in my identity, I know who I am, and that may not align with you know, the next person's or somebody else's, but it's still valid for me because it is my journey and it is you know, mine. It's not anybody else's.*
>
> *Bastian*

For many participants in our study, transition was not a linear journey from A to B. Some young people identified with traditional narratives and pathways of early identification but felt that this wasn't the case with everyone.

> *It's been difficult to covet my own space in that trans space. I think because the trans community is often in such a place of constantly being under suspicion, constantly being like drawn out for whatever reason and like constant abuse towards the trans community, it means that we're often in a space where we can't accept different narratives and some people. Like it means that certain narratives if they don't ascribe to the trans, the trans narrative then it becomes invalid.*
>
> *Afi*

A few participants felt a lack of understanding for transgender diversity was due to poor representations of trans people in the media, which contributed to them feeling 'under suspicion' in society and more generally fuelled the 'constant abuse' of trans people. It was felt that a focus on medicalised pathways and one type of transition also contributed to sensationalist media headlines and prejudiced articles (and vice versa) (see also *Chapter 5* for more on young peoples' views on the media).

Diverse healthcare pathways

Stereotypical medicalised pathways strongly influenced how participants felt about their journeys and healthcare options. This medicalised pathway was characterised through the lens of a psychiatric model of gender dysphoria and a historical, stigmatised notion of gender dysphoria as a disorder or illness.[87] Traditionally, the medicalised model has conceptualised gender dysphoria as something that could only be relieved or treated through medical treatment and intervention with hormones and surgery.

> *When I was younger, my idea of the trans narrative was like, okay, come out, get a binder, get referred, top no, shit, the other way round. Start hormones. Top surgery. Bottom surgery. Happiness. It is not like that. It is so not like that.*
>
> *Bo*

> *Everyone's journey is very different … I mean some people are trans and they decide that they don't wanna have any like medical intervention with hormones or anything like that and that's perfectly valid, that's just as valid as someone that has bottom surgery and top surgery or whatever.*
>
> *Eaton*

Encountering a dominant and particular medicalised model meant that young people felt this was the only pathway that existed. Participants described how this influenced their first impressions of what to expect when coming out as trans. This focus made young people feel that any other trans journey that did not fit within these parameters was not as acceptable. It was important to young people that all trans journeys, whether receiving intervention or not, were validated and respected within healthcare services.

> *I do feel as though there is a specific, certainly from the start of transition there is a specific journey that you're sort of expected to go down. You are expected to start with the social and legal and hormones, you are expected to then have surgery. I feel as though there needs to be more acceptance of much more fluidity. You don't have to have surgery, I might but you don't have to. It's not something that is essential to being trans.*
>
> *Celia*

Some participants felt that healthcare practitioners relied on traditional notions of gender non-conforming experiences in childhood that had to be met, otherwise support could be denied. People's experiences sometimes did not fit this mould, and they wanted healthcare services in the UK to accommodate this. Moreover, non-binary participants who were seeking health care or undecided about medical intervention did not feel there was a service or space that looked after their needs. A few participants felt a pressure to conform to binary expectations of gender expression based on stereotypes of masculinity and femininity.

Non-binary healthcare needs

Twelve participants we interviewed were non-binary or genderqueer. Non-binary people were frequently discussed as a particular group whose needs were currently unmet in healthcare services. It was felt there was a lack of professional knowledge about what it meant to be non-binary and what a non-binary transition might look like.

> *[Healthcare services] struggle sometimes with non-binary people. They struggle sometimes with the idea outside of … binary life … obviously we do exist*
>
> *Maddox*

> *I don't know any non-binary person who has had an easy relationship with accessing hormones, just because a lot of people expect you to have a binary transition. A lot of people expect you to just want to be a girl or want to be a boy. The idea of stopping hormones at a certain point once you have achieved some of the things you want I think is something that we need to get more used to as opposed to the idea of a lifelong commitment to things. Because there are non-binary people who want it for a certain period of time.*
>
> *Sky*

A few non-binary participants stated that health professionals have little knowledge about non-binary identities and that much training excludes non-binary identities from their models of health care. This could include only wanting hormones 'for a certain period of time' or wanting hormones in smaller doses, or only wanting some treatment but not others. Transitioning as a non-binary person felt difficult and complicated and those participants felt excluded from general trans healthcare discussions and ostracised from NHS services.

Fears of not being 'trans enough' when accessing health care

Expectations around conforming to a dominant narrative of trans health care meant that coming to terms with being trans, deciding about healthcare options and which pathways to take led to an anxious experience for many young people. Many participants in our study discussed internalising this pressure as a fear of 'not being trans enough'. This was a pressure that was present with them through healthcare services as well as in trans communities and support groups they participated in.

> *I was worried going to the support group that I wasn't trans enough. If I didn't dress masculine then I wasn't trans enough or if I didn't, if I wasn't absolutely certain about my gender then I wasn't trans enough.*
>
> *Oscar*

> *So yeah I don't know, sometimes I have that 'are you trans enough' voice in your head, like 'am I non-binary enough,' and I'm like, I don't know what that means. But I guess because I don't fit into a narrative and I'm not you know, I'm not kind of at the point where I'm considering any kind of more medicalised intervention, and I'm kind of just sitting where I am and figuring it out and being, you know trying to be me as I exist.*
>
> *Jessie*

> *There was another massive pressure to dress a certain way and to use make-up in a certain way and to all this sort of stuff. But just doesn't fit with like my reality*
>
> *Lina*

The fear of 'not being trans enough' was a constant for many throughout their transition and daily lives. It impacted their healthcare decision-making and seeking support. Young people talked about how there was no room for doubt, confusion, or exploration which was something they felt was not well tolerated. At the same time, they wanted to be validated and valued as trans by healthcare services, as well as in society. Conceptualising trans experiences as an A to B journey meant that young people felt they had to achieve particular 'milestones' along the way in appearance and in their attitude towards transition.

Trust in National Health Service models of health care

Participants in this study often referenced how the medicalised model of trans journeys and healthcare experiences was reinforced by the specialist gender services in the UK. There was a feeling of needing to be 'a good trans':

> *[I]f you want to go get healthcare from the NHS or change anything legally or anything, they will often ask you or so I've heard, they ask you questions about like when did you first realise this. You're supposed to have this kind of picture perfect like Princess and the Frog story about like, oh, I realised this when I was five, and it's doesn't work out for everyone. It's not how most people's lives are. And so, there is this kind of, you've got to be a good trans or else we will not give you healthcare whereas it should actually be accessible to all. I think that almost kind of dilutes the waters in terms of trans culture because since many people have to pretend to have these kind of stories and perfect narratives in society in a way just to get by and like survive in the legal sense. It kind of homogenises the trans experience when in fact it's a very diverse thing and no two experiences are alike and that's why it's important to get those voices out there and get stories told and stuff.*
>
> *Alexa*

> *A lot of the time, you're kind of, there's like a pressure almost to have the narrative of I hated my body, or I hate my body all the time and I never wanted to be like a girl, or like I always had short hair. And it's not the narrative for so many people. I felt that a lot of my non-binary friends when they went to [the NHS clinic] they felt that they had to fit into a binary narrative when that wasn't them. So I feel that like it's important to have your own individual narrative rather than try to conform it to like someone else's or what you expect a trans narrative to be like.*
>
> *Archie*

A lack of information about what to expect from NHS services and a lack of trust in cisgender practitioners often resulted in young people preferring to trust what they had heard from other trans people. Participants in the study talked about their caution when accessing gender identity services due to the perceived conceptualisation of transgender identities and healthcare needs. This was particularly felt by those participants who were non-binary or genderqueer.

> *I find that accessing services that are to do with trans healthcare are really jarring because you often have to be thrust into a situation of dealing with cis people and their cis ideologies about what gender is. And especially with like the NHS, like I've been through their service before and it's a lot to be a very specific kind of trans and a very specific kind of person for them to be able to give you access to care, because you're not able to pay for it yourself. So if you are in a situation where you're not paying for it yourself, you have to go via the NHS route. There are these certain hoops that they make you jump through that are not fair barriers, I don't think, when if given the alternative people would, well can just bypass that situation and still claim their identity as their own because nobody is taking it into question at that point. It's about whether or not you can, you've got the money.*
>
> *Maddox*

Participants expressed discomfort in having cisgender healthcare professionals responsible for navigating their healthcare pathway. They perceived cis professionals' understanding of trans lives, bodies and experiences was limited and drawn from outdated sources. People spoke about their experiences of 'gatekeeping', where professionals controlled or limited access to NHS services. They felt they would not be believed to be trans if their experiences did not conform to a binary or traditional narrative, and they would also be denied treatment if their experiences did not fit. Participants suggested that other trans young people 'bypass' and avoid NHS routes and seek other means of accessing hormones.

> *I really think a lot of the narratives, I think they're harmful, really I think they're restrictive. I think they serve a standard that trans people are expected to follow and I think the [GIDS] plays a part in like setting up that. That sort of standard of you should have this narrative, you know, 'Oh when did you first find out what being trans was?' and 'Oh when, when did you first feel this?' and I think the [GIDS] especially for them you need to make up, not make up but, but you can see these completely innocuous events that didn't really mean anything and then they make you go through it with sort of 20/20 hindsight. And then*

> *you join up all these dots and connect it and all of a sudden it all makes sense that you are trans. But I think in reality that's not true.*
>
> *Reagan*

Many believed current gender specialist services reinforced a medicalised narrative that was 'harmful and restrictive'. These models concentrate on linear, consecutive events that 'ticked boxes'. Participants felt that the rigid model of gender dysphoria that informed NHS treatment options did not fit with their understanding of themselves. They felt mounting pressure to conform to these stereotypes.

> *You may feel pressured to lie to get access to what they want because they know that a lot of doctors are expecting a certain narrative and if the narrative doesn't fit what they expect then they won't get what they need. I think that kind of really should be taken away I think ideally in the UK we should have a system that's yeah like, what's the word, sorry I forget the term, informed consent. I don't think it should be up to one clinician or two or three clinicians to analyse someone and say yes this person is trans and I think they should get on this treatment or no this person I don't think that they're trans and shouldn't be on this. I think people should be able to be informed of the kind of risks, the benefits, the outcomes, the potentials and then if they feel they are able to make that choice and they want to make that choice then that is their decision. I don't think it should be gate kept the way it is.*
>
> *Heath*

A few participants revealed how this pressure compelled them to lie to healthcare professionals to have their healthcare needs met. They talked about how trans young people can sometimes hide important parts of their experience because they are afraid of being denied care and options.

Participants wanted an 'informed consent' approach to trans health care instead. They criticised what they perceived to be a large amount of gatekeeping in current NHS services. This approach works on the basis that rather than having to meet certain criteria to be 'diagnosed' with gender dysphoria, healthcare practitioners in primary and secondary care work with trans patients equitably, to understand their needs and how to meet them.[45] The intention is that by providing all the relevant information such as risks and benefits of treatments this allows shared decision-making with patients make their own informed decisions about treatment.

In summary, participants we interviewed described how they perceived current gender identity services to uphold rigid notions of what counted as gender dysphoria. This has become a high threshold for those trans patients who wish to receive medical treatment. Participants were keen to highlight diversity and variation in young trans experiences that deviated from outdated psychiatric models. They advocated different ways of identifying as trans outside of dominant and traditional gender dysphoria narratives, with many feeling that there needed to be a broad range of healthcare options open to trans young people and adults. Participants experienced multiple journeys and wanted this insight to help guide the structure and planning of NHS gender identity services.

Health care and inequalities

A key theme in interviews was a discussion of the inequalities caused by current failures in the healthcare system. Lengthy waiting lists of over 2 years for gender identity services and a lack of support or healthcare options meant that many young people tried to seek out different options, of which there were few. Private healthcare services had steep financial barriers not available to all. Other participants turned to self-medication.

Furthermore, gender identity services and healthcare services in general lacked the competency to work with and did not adequately meet the needs of TPOC, disabled trans people, autistic trans people or those who were working class or low earners. Participants advocated for a robust understanding from healthcare professionals about the additional needs of marginalised groups within the trans community and the barriers to accessing and receiving competent health care.

Accessing services and barriers

Participants felt angry, hopeless and frustrated at the multiple barriers to accessing health care:

> *I can't afford any kind of private healthcare, and you know not, I'm not provided that through work or anything like that. And especially for like ongoing like, like chronic illnesses and stuff like that, where it's like maybe you'll need a treatment change, and you know how much is that going to cost … it has felt really hopeless at points you know. It's really felt like you know you'll, you're screaming at people like this is, this is my life, like this is my daily life, you know, and in the ten minutes that I get to see you I'm trying to sum it up so that I can find some support. But outside of those ten minutes, it's every second of my day is these experiences, and these difficulties, and to not be heard is, is really hard. Like it's really like well what do I do? Where do I go? Like how am I supposed to survive?*
>
> *Sharnaz*

> *It's the difference between life and death a lot of the time and so I think that so many trans people have to go private in order to get their basic healthcare, it's disgusting. However the way the NHS is funded and like I said, I've been waiting two years and haven't heard a word just means that it's the last resort for a lot of, a lot of trans people. And so until like they fix the funding model I can't see any other way of people being able to get their needed healthcare.*
>
> *Afi*

Many participants in our study felt there was no timely, tangible health care available for trans people. Paying large costs for private services was viewed often as a 'last resort', which many couldn't afford. They also revealed how there was no support during the waiting period for NHS services.

> *By taking all of these quality services and dispersing them in this like nexus of like time, administration, of cost, of location and all these different things. What would have otherwise been a really good collection of services it's kind of obfuscated it's sort of like hidden away under this layer of stress so that the services seem bad and you desperately wanna like reach out for anything else.*
>
> *Sky*

Participants able to afford and access private healthcare services were aware of their relative privileges. Some participants were able to acknowledge their advocacy skills such as being educated in medicine and healthcare treatment and confident to communicate with professionals when making decisions about their well-being. It was this cultural and social capital that meant that some participants could accrue relative advantages:

> *I'm white. I'm privately educated, more than that, I'm a medical student. I know how to navigate a consultation. I know what I'm entitled to. I know how to ask questions. I know how to seek out services.*
>
> *Haydyn*

Participants also highlighted the inequality in accessing healthcare information that influenced how existing services were run and who the information was targeted towards. Tai talked about how there was a lack of healthcare information written for TPOC and disabled communities, much of the trans narratives were focused on white, able-bodied trans people.

> *Most access … sits with the people most privileged in a marginalised community and so most information in the [trans] community is written usually by white non-disabled, … trans people. Or, or when it, and that's if it's lucky enough to be written by any [one] of us, … it's written for them. And so I think there's a*

> *starting point of like even having those experiences recognised in trans made or made for trans people that actually acknowledges different experiences and the different barriers [within the trans community]*
>
> *Tai*

Racial inequalities and trans health care

As part of this study, youth advisory panels were held with groups of young trans and gender-diverse people of colour to highlight the specific healthcare needs and experiences related to race, racism and cultural differences (see *Chapter 3* for more detail on panels). The young trans and gender-diverse participants we interviewed highlighted the many racial inequalities reinforced by current trans healthcare services.

> *I think that BAME [Black, Asian, Minority Ethnic] trans people need to be prioritised in sort of like all aspects of life like really like, you know, for equity to exist like people need to make sure to platform us, to sort of share our story, to listen to our experiences, to you know more funding opportunities.*
>
> *Lin*

> *As a black trans person you should be definitely out there saying that your life matters and that you exist, and that you're here struggling on your own with no access to services and care.*
>
> *Maddox*

> *We cannot have a white middle-class narrative being the thing that drives what it is to be trans. Some of that is access to the history and information about the fact that you know women of colour, transwomen of colour have always been at the heart of the trans right[s] movement, is very important.*
>
> *Darby*

Young TPOC had messages of hope and solidarity for others in the community as well as calls to action for healthcare services and practitioners (see also the 'Race, culture, religion and healthcare' tab on the Healthtalk.org web resource).

Lack of cultural competency

Participants described healthcare practitioners lacking the knowledge, skills and understanding of working with black and ethnic minority trans people, with some reinforcing racism within health care. Participants were keen for others to be aware of the multiple barriers that faced TPOC accessing healthcare services.

> *It's not hyperbolic to say that the healthcare system is racist, or that it, you know that cultural considerations are rarely factored in.*
>
> *Tai*

> *I guess my kind of like main concerns is the like cultural competency around gender from GICs and like how, yeah. I guess like I'm really aware that the GIC system is like rooted in, like a, a kind of like, what's the word like, conservative Eurocentric idea of gender. And that like whilst things are sort of changing a little bit around like a more, I can't say flexible because GICs are anything but flexible, more in terms of like recognising multiplicities of genders ... Like do the GICs actually provide the kind of support that trans people of colour need? Do they really understand what the, how the cultural differences manifests for us and what they mean.*
>
> *Diya*

> *I think that like the whole coming out thing and being visibly, and what it means to be visibly gendered in particular cultures, is very different depending on what culture you are in. And I think if you're like me*

> *and you live in England or you live as a second generation or third generation young person, where your parents, or your parents' parents are not from this country, and are not from here, you have cultural biases, you have cultural applications many of which are down to colonisation I may add, that attribute massively to how I'm experienced as a person.*
>
> *Maddox*

People of colour participants felt that 'cultural considerations are rarely factored in' to gender identity healthcare services. They spoke about how much trans health care caters primarily for those with the most relative privilege; able bodied, neurotypical, white trans people. Participants said that trans healthcare needs to understand the additional barriers that face more marginalised groups.

Diya talked about how the model of trans identities adopted by NHS gender services is based around a 'conservative, Eurocentric [focusing on Europe at the exclusion of other parts of the world] idea of gender'. Participants felt that gender identity services should have a more 'flexible' approach to understand diversity.

Racist assumptions in health care

Participants talked about how a lack of understanding about cultural diversity in health care enables racist assumptions to permeate healthcare provision and impact the experiences of people of colour patients.

> *I felt like he [a doctor] said something weird about like my race … it was something about like whether I'm gonna [have a] keloid scar or not. But like the way he said it was like hella unnecessary and like other practitioners spoke to me about like keloid scarring in like black communities and like in like Irish communities or whatever. But the way that this one said it I just felt really uncomfortable and was like you didn't need to, that was like quite uncalled for.*
>
> *Afi*

> *Having sickle cell anaemia, which does not commonly affect white people, but I am not white. So, that's been a bit of a nightmare … when I have to have blood tests there or information, the amount of times they've said, I'm sorry, you've ticked the wrong thing on your sheet or you can't have sickle cell and I'm like ah, but I do, well look I do. Like just the amount of assumptive bias, really. They assume one thing and then go, ooh no, that's also not it and against their own sort of profile then they go, ah, that doesn't fit with my notion of what I think you are.*
>
> *Bastian*

Participants spoke about their experience of healthcare professionals making unhelpful assumptions based on race.

> *There was, I think there was more assumptions made of how supportive my family is. As I was saying, there was that psychiatrist … almost refused to sign for me being allowed to go on hormones until I could guarantee her that I would come out to my parents. I think that was very much related to the fact that she was worried that my parents are very religious and very strict. And that she had this kind of I think assumption that it would have dire consequences for me if I came out to them or they would react very strongly or throw me out of the house like this kind of assumption.*
>
> *Sanjay*

Participants also described how a lack of knowledge of cultural differences led to 'microaggressions' (implicit, everyday words or behaviours that are derogatory or hostile) and assumptions based on perceived culture or religion. For example, participants spoke about being strongly encouraged to come out to a religious family before checking whether this was appropriate and, conversely, assuming that parents would not be accepting because of religion was also unhelpful and stigmatising.

Medical racism

A key facet to perpetuating racial inequality in health care is the racism inherent in medical training and university courses.

> *I think medical racism ... is a genuine thing ... you know these archaic text books as well, ... the understanding of like that there is differences in the sense of what ethnicity means, and like risk factors and stuff like that.*
>
> *Rani*

One participant of colour who also had experience of medical training talked about a lack of teaching on cultural differences in their learning including different health related risk factors:

> *[A] lot of PoC learn to, to hide pain, if that makes sense. They learn to like minimise the pain they're feeling ... like white people will, if they get ill with just almost anything, a lot of the time they will just rush to the doctor, like straight up, and that's because they feel comfortable and confident doing so ... I know I've been bad for it, I've minimised my own pain, even though like I should go to the doctor for something, like you know, and, and I'm terrible for it ... I'll tell other people to go to the doctor for it, but when it comes to myself I'll minimise it for myself because like I don't want to put, I don't want to be a burden essentially. That's the issue, and like a lot of, it's kind of an entrenched kind of, well I don't know, maybe it's a thing within, I guess it is, it is a thing within like PoC communities where like the sense of being a burden is an, a worry, especially on like, because like on your family or something. Like you don't want to add more cost or anything like that, or like cause more issues and that's, that's the thing that you kind of want to avoid.*
>
> *Rani*

Race and representation in health care

Another of the key ways that racial inequalities were perpetuated in trans healthcare services was the lack of representation of TPOC in all areas of health care. This included in healthcare information, medical training, staff, support services and beyond (discussed below). Trans people of colour in the study sample talked about the lack of representations of TPOC in health care and the impact this had on them.

Healthcare information

The experiences of TPOC were missing from much trans healthcare information which meant that some people could not relate to examples or envisage their own healthcare journey.

> *If I'm honest with you, most of it was very white so I didn't really, I just took the basic information, but I didn't hear about people's experience and couldn't relate to that at all.*
> *I: What couldn't you relate to?*
> *R: Just kind of, I don't know, the life story, I suppose 'cos mine is quite, well not specific, but actually I don't know how to explain it. I just couldn't relate to it. Obviously, you can relate to people who you see yourself in. I couldn't live their life and they couldn't live mine.*
>
> *Connor*

Participants described how most information available to trans patients was 'very white' and centred around the experiences of white people.

> *They show you like this like, this is not, obviously not exactly what they're called, it's like a big book of vaginas, or whatever, of like a big book of vulvas, in terms of like cosmetic appearances after surgery. And I think it was like they're all, like people, like white people's like post op vulvas, and I was like, Oh, this is, is this, does this say something about like trans people of colour not getting the healthcare that we need? Or*

> *is this just like the classic like whiteness is a, you know, the blinkers of whiteness, not paying attention to lack of diversity.*
>
> *Diya*

The effect of mainly white bodies and white examples meant that those who are not white feel shut out and their needs unimportant. When one participant attended a consultation on gender-affirming surgery she was presented with surgery outcome examples based on white bodies. She felt this represented a lack of competency in the gender services in meeting the needs of TPOC.

> *I didn't grow up with media role models of what queer Asian masculinity looks like and then to add the sort of like extra sort of like dimension of being trans onto that and being bisexual onto that. Did not really grow up with the conception that someone like me could exist with all of my intersections like I think, felt kind of impossible that like someone could have all those intersections and still have, yeah and exist because it's just I've not seen anybody out there with this kind of experience.*
>
> *Lin*

These feelings were exacerbated when belonging to additional intersectional groups such as being non-binary, gay, bisexual, disabled, autistic and/or working class. Trans people of colour talked about not seeing themselves represented in healthcare services contributed to feeling like they could not exist and there was not a place for them or their healthcare experiences.

The importance of visible staff

A key theme that TPOC felt was the lack of representation and not being able to meet with or be seen by healthcare professionals and staff who were also people of colour. Some felt this was to do with opportunities for training:

> *I haven't yet met a non-white healthcare professional working on trans health.*
>
> *Tai*

> *it's difficult as a black person trying to access any form of healthcare or support that is from like another person of colour, from a black person is again like very difficult and having them understand trans issues or being trans that kind of stuff is like additionally difficult in in like a racial sense. So yeah I guess those kind of additional barriers to accessing healthcare are the things that come to mind*
>
> *Afi*

> *It's a lot less likely to see people in the trans space that look like me, but that doesn't mean that they're never going to be there. It just means like healthcare professionals unfortunately it seems like yeah, black people don't necessarily have access to the same resources when it comes to going and doing degrees to then be psychologists and do things, and have outreach worker. Maybe if I was just a white trans female there'd be more people that are willing to hear my voice, and my experiences. I feel like as a black person your voice is already marginalised, and it's who you're speaking to and the way that you're perceived.*
>
> *Chanel*

It was often described as feeling disappointed and sometimes uncomfortable having to share personal and intimate details to only white healthcare professionals. Participants talked about how they struggled to relax around white professionals, or that their race was invisible.

> *Spending an hour or two, I can't really remember, in an office with this white guy I've never met before, having to talk about like my sexual preferences, my sexual histories, my family history, mental health history, trauma, like and then to get an official certified pathologisation at the end of it.*
>
> *Tai*

> *I think for me it was, I don't know, having a session with someone who can understand where you was coming from. Like I did have counsellors before in uni, but she was a white middle-aged woman kind of middle class sounding and the things that I was telling her clearly didn't click. Like she couldn't, not that she could relate to, she just didn't know what to do. I didn't really get much support, any useful support from her at all. I didn't feel, I felt worse afterwards. It was not her fault, but I just did not feel good afterwards. Like I poured my heart out and just get nothing in return, so that, yeah, that wasn't good. But for the latest one, she's you know, South Asian lesbian woman and kind of understood, kind of had like similar experience with family and kind of similar background, you know, stuff like that. So, she could understood where I was coming from and give advice based on that. So, yeah. I think basically having someone that you can relate to or someone who can relate to you as well. Back and forth like I said, not like in a one way.*
>
> *Connor*

> *My blackness was not really something that I got to address with them, it was just literally here's my experiences.*
>
> *Chanel*

For Connor, having a counsellor with a similar background who showed racial and cultural understanding had a profoundly positive effect. Participants recalled in some encounters with health professionals, how important experiences were ignored, pushed aside and left out of the discussion. Meaningful experiences that could aid support and well-being were kept hidden and private due to mistrust.

> *I feel like it was good that I had a black woman to speak to, who had been around other trans people.*
>
> *Chanel*

> *My doctor is a brown man, which I appreciate. I think it makes me hyper aware of that kind of stuff, like when approaching [private provider], I was very specifically like, 'I want a person of colour psychologist, I'm going to speak to them.' Because it's a lot of energy speaking to white people and it's a lot of energy being able to share this kind of stuff with the space that maybe like I was talking about before, that can't relate. So like a cis white masculine person in my head is like the furthest away from a person that I know how to deal with.*
>
> *Maddox*

> *[My counsellor is] from, I think she's got Indian heritage or something like that. Like I said, she was a lesbian. She was a masculine woman as well, so it's kind of understood like kind of overlapping, not identities but like experiences. But and I don't know I just felt like she gave me not generic advice but advice that would make sense with my cultural background, because she also lived it. So, yeah, I think that was, that really made the difference for me.*
>
> *Connor*

> *I just felt like [the counsellor] understood the issues that I faced with my Dad's side of the family, with how they accepted me. I can't, I wasn't inside of her brain, but she was just a very understanding person, like she listened, she heard, and so actually I'm so sorry like that trauma comes up as well, but she had time to listen to this, because she understood that that's, it contributes towards my gender identity like it contributes towards the way that I process things.*
>
> *Chanel*

Trans participants of colour valued the times when they were able to work with healthcare professionals who were also people of colour. They felt this improved rapport, deepened the understanding and help form a more meaningful alliance. Participants felt like practitioners who were also people of colour were more likely (though not exclusively) to understand their experiences and their support needs.

The pressure of representing others

Trans participants of colour also highlighted how cultural and racial stereotypes impacted their transition and healthcare journey.

> *If I was a white person I would be socially transitioning from being seen as female to being male in society, and you're moving up a privilege, you're getting access to so much more. You have a whole different way of dealing with the world from that standpoint. Whereas for me moving from not a disadvantaged perspective but at least a perspective of, it's not level footing, it's not equal ground, a woman, a black woman in science is hard enough to exist never mind a black trans man, trying to figure out, or a non-binary person in that space. I feel like my masculinity and my narrative as a black person have to constantly be engaged with when I'm out in the world because I'm viewed as a certain thing. Like if I move around with my white friends they move around as white people as individuals, I move around as a representation for all the black masculine people that exist in the world. I have to be a good one, like I've got to be a good experience for anyone who comes into contact with me, and that's a huge weight to carry all of the time on top of the weight of gender and the weight of the binaries and then the weight of my fucking chest itself.*
>
> *Maddox*

Maddox discusses the pressure to be a 'good' role model in their transition. Trans participants of colour talked about how moving between and being perceived as another gender as a black person is a complicated process that created further challenges. Because of racialised gender norms it could be much harder for a trans person of colour to navigate and negotiate these pressures and find a space that they feel comfortable in.

Disability and chronic illness

A number of participants we interviewed talked about inequalities they experienced being trans and disabled. Participants talked about important issues that need to be taken into consideration for disabled trans patients as well as their experiences of bias and discrimination in healthcare settings and difficulties with accessibility.

Some disabled participants and those with long-term conditions talked about how this impacted their transition.

> *I find that binding takes a bit more of a toll on me than it does for a lot of people. So, because my ribs and my spine essentially aren't completely happy with sustained compression I can't bind for as long as a lot of people and, and that sort of thing. And less so for me, but I know another person who has Hypermobile Ehlers-Danlos Syndrome and is non-binary. They would prefer to wear trousers most of the time. But their skin is very sensitive. So it is much easier for them to wear skirts when that's not how they want to present, but the skirts don't kind of rub against their legs in the same way and so, cause, all that pain.*
>
> *Lake*

> *I have a fibromyalgia which makes it quite painful to bind sometimes so often I do skip out on binding because it's too painful or restricts my ability to kind of move around more than I'm able to which make me feel really dysphoric. But, you know, it's kind of the comfort versus safety, sorry yeah comfort for myself versus like the safety of not binding for too long which is a drawback.*
>
> *Heath*

> *I am disabled, I have myopathy, so my muscles don't work as much as they, as well as my peers. It hadn't affected my transition as such. It's been a factor in terms of I've mentioned it when I've medically transitioned but It hasn't actually affected my transition.*
>
> *Celia*

Some participants were unable to bind (techniques to make chest look flatter) for long periods of time or at all because of pain. This meant that gender-affirming surgery such as chest reduction surgery was more of a priority for those wanting to relieve the discomfort. However, for some participants being disabled was unrelated to their experiences of transition.

A few participants talked about their experiences of chronic illness, including chronic fatigue, endometriosis and polycystic ovary syndrome (PCOS). Many participants felt not believed and belittled by healthcare professionals.

> *Chronic fatigue which they've all, they all kind of kicked off at the same time. I think that the fibromyalgia was the reason I was ill as a child quite often, but didn't really know why. And yeah so, but they, they're all the kind of, they are all illnesses that people don't really believe in, so my entire existence is not real, in a lot of senses. You know non-binary people don't exist, now I'm too young to have endometriosis, I, you know fibromyalgia's a made-up disease, like chronic fatigue is something you know, well everyone gets tired, so it's one of those things where it's just a constant, like do you know what I don't have to validate myself to you.*
>
> *Riley*

> *I mean if you, you walk into a, a doctor's place and you go, 'I'm trans. I'm queer. I'm disabled and chronically ill and mentally ill.' And they kind of go like, 'Okay, well, that can't all be true,' essentially.*
>
> *Lake*

Participants reported scepticism from health professionals when they presented with multiple disabilities or chronic illness. This was especially for non-binary participants. Some gynaecological chronic illnesses such as endometriosis, posed problems for transmasculine and non-binary people who felt shut out of support and were frequently misgendered. Their bodies were not provided for, or acknowledged in that space.

Overlapping experiences and autonomy

Disabled trans participants talked about their experiences of being treated with a lack of autonomy and respect by healthcare professionals. This was a particular experience of disabled TPOC. Participants experienced more difficulty being believed by practitioners.

> *My gender and perceived gender came into play there for sure like being south Asian, you know, person who was being perceived as a woman, … and being disabled, and like chronically mentally ill, right, and it's always this thing of like, 'Yeah but like, are they really telling the truth?' Like, 'Things being blown up out of proportion,' They just weren't interested in in trying to find out what was going on, and they kept saying, 'Oh it's stress, it's mental health, and blah blah blah.' And it's like, and we know that that happens with like chronic illnesses in general, but it's made worse if a) you're AFAB [assigned female at birth], or read as a woman, and, and b) if you're a person of colour, like, your experiences with it and healthcare are so often dismissed.*
>
> *Sharnaz*

Participants reported that their healthcare experiences were often not taken seriously.

> *A lot of AFAB [Assigned female at birth] people like obviously have well, a lot of them, PCOS (polycystic ovary syndrome) is way more common than people realise, … And similarly with endometriosis, and that's another one. And it's a particular issue for trans folk in a sense because testosterone obviously eventually people on testosterone will need to get hysterectomies, and it could be an issue, especially for PoC people for people who minimise their pain, for when that hysterectomy may be necessary. Because there is,*

> *essentially you can, you will need to have it, but when is the question, and there is the, you don't want to be too late … it's a risk … one of the things like we really need to improve on in trans healthcare in general is things like hysterectomies, like such a delay even, like surgery wait times and stuff, it's ridiculous … it could mean like a difference, like in, a marked difference in like healthcare.*
>
> *Rani*

Rani discussed how these issues can particularly impact trans patients with PCOS and endometriosis. She highlighted how if people learn to minimise their pain through numerous experiences of having it dismissed, there can be serious health consequences for some trans patients.

Autism and neurodiversity

Inequality and discrimination in healthcare services was a key feature of autistic and neurodivergent trans people's experiences. Young people we interviewed talked about being trans and autistic or neurodivergent and how it impacted accessing healthcare services. Autistic participants talked about needs they had that healthcare professionals should take into consideration.

> *[Practitioners at GIDS] said that, because I wasn't emotional about it, I wasn't like crying in every session that I just, I didn't seem that bothered by it. Like I didn't seem like I wanted it, but just because I'm not crying about something it doesn't mean, that doesn't mean anything. It just, just cause I don't cry it, it doesn't mean that I don't want something.*
>
> *Kyson*

> *I find it, with mental, with medical professionals, I find it difficult to defend myself sometimes.*
>
> *Oscar*

> *I find it really hard to look people in the eye.*
>
> *Tami*

Kyson described how healthcare professionals interpreted that they were not emotionally invested in the outcome of his transition, which was incorrect. Oscar talked about how his communication issues in a consultation meant he found it difficult to defend his choices and decisions to healthcare professionals. Participants also talked about non-verbal cues such as eye contact in consultations. Others talked about sensory issues with make-up.

> *One thing that came up a lot with the gender identity development services was the fact that I didn't wear skirts very much. I've never worn a dress. I don't wear make-up or anything … the main thing with skirts and dresses is that my body shape is not like the shape that those clothes were designed for really. So, the way they like sit on my body feels uncomfortable and I don't like it very much … Trying to show how much of a trans woman I am by wearing a skirt or wearing a dress and it just doesn't feel worth it because it doesn't feel that comfortable. And then with make-up it's the main issue with that is that I have tried a couple of times to put make-up on. I've never gone out wearing any make-up or anything. Since I've never really done it before, I am terrible at it and since it's something that basically just need to keep doing over and over again until you get good at it. Since I don't feel any pressing need to wear make-up and I don't especially like how having it on my face feels because yeah. Got difficulties with sensory stuff as it is and then also having to try and put stuff on like try to do anything with my hands, like my hands sort of shake a bit all the time generally and then trying to do something precise with them makes that worse*
>
> *Lina*

Health professionals made assumptions that participants felt ignored their needs as neurodiverse patients. Lina felt her trans identity was invalidated by the gender specialists she saw at GIDS.

A few autistic participants celebrated some of their autistic traits and what it brought to their healthcare experiences. Kilan talked about being good at 'understanding complex information' which helped in healthcare encounters and understanding options:

> *It has made it quite a bit easier because I really do like learning about things. I am comprehensive when it comes to understanding complex information. So it's very easy for me to decipher it quite easily. When it comes to that I am quite good at being able to understand and memorise, understand and use that information in a way that benefits me quite easily.*
>
> *Kilan*

Discrimination and lack of autonomy

Young autistic participants talked about the discrimination they had experienced in consultations at gender specialist services.

> *It [GIDS report] was probably like the worst thing I'd ever seen written about me or anything like that. It was just, it was a consistent like seemingly wilful misinterpretation of just everything that I told him and everything about me. It was like a mix of the stuff that was just like blatantly false like not having any trans friends when at no point did he ask me if I did or not. He just wrote this in anyway that he didn't have any friends. There was misinterpretations of stuff like me saying that most people at school didn't know who I was, to mean that I had a limited social circle when it was like I had no reason for, no reason to interact with the vast majority of people at the school because they just had nothing to do with me ... And then there was the recurring thing throughout of the idea that my parents shouldn't have like unconditionally supported me from the start and that, the, it's as if he was trying to portray it as if they pushed me into being trans or seeking support from GIDS. There was one bit about how my gender presentation was at odds with my female identity, which is odd since [I] don't know really know how a gender presentation can be at odds with female presentation because that's kind of the point of androgyny. So, that was interesting. There was also the consistent, it was just a consistent building up of this narrative of me as this like autistic trans woman who didn't understand herself and didn't make her own decisions and had no autonomy. It was really strange, uncomfortable and pretty cruel piece ... that was just so completely inaccurate and felt like offensive at one point, at one point, clearly one point where I was described as having my gender presentation was described as 'lacklustre.'*
>
> *Lina*

In this way, autistic participants talked about experiences with gender identity services where they felt their autism had been used against them in the assessment process for accessing treatment. Furthermore, many participants felt being autistic was used by practitioners to discriminate through invalidating their experiences and denying them treatment and access to medication.

> *I feel like it happens a lot with autistic people, where they'll be like knowledgeable of what their needs are and what care they need, but doctors won't kind of listen to them purely because they feel like, 'Oh this person's autistic, they don't know what they need.' That kind of thing.*
>
> *Rani*

> *There is a big thing when it comes to trans healthcare stuff, where people with neuro-divergent stuff are terrified at saying so. Or terrified of getting assessed for it before they go through the gender pathway because there has been reports of people being turned down because they believe that it is something to do with autism. Or that their autism diagnosis could be held against them ... people with autism spectrum disorders, like they know themselves, just as much as anybody else does, you know. Like I've never met an autistic person who's just like, 'I don't know about me.' They tend to know who they are in very strong ways*
>
> *Paige*

Participants talked about the fear and mistrust surrounding neurodiversity and healthcare services.

> *With GIDS it was mostly the psychologist effectively saying that he thought I had, I was autistic. And basically, using that to try and sort of infantalise me try and remove any autonomy I had about anything and then to try and use that to try and bar me from seeking the healthcare that I needed.*
>
> *Lina*

Autistic participants talked about their experiences of infantilisation (treating somebody as though they are a child) by healthcare practitioners. Autistic trans patients often felt that they lacked autonomy in consultations in gender identity services.

> *When it like Autism and stuff like that or ADHD [attention deficit hyperactivity disorder], or any kind of disability, because I feel like it happens a lot with Autistic people, where they'll be like knowledgeable of what their needs are and what care they need. But doctors won't kind of listen to them purely because they feel like, 'Oh this person's Autistic, they don't know what they need.'*
>
> *Rani*

Conflating gender identity and autism

Misinformation surrounding autism was discussed and how it was often conflated with gender identity or posited that autism caused gender dysphoria.

> *I remember being at CAMHS and they were doing some form thing like doctors always do. And they said something about clothes and they were like, I can't remember exactly what it was, but it was something to do with the way I dressed and they were like, 'Oh, do you think that's to do with your autism?' And I was like, 'Why, why would the way I dress have anything to do with autism?' ... I've been told in the past that I'm not actually trans. It's just because I have autism ... It was implied by [GIDS] and then it was said by teachers at school when I said about changing uniform. But obviously they are not healthcare professionals I don't really care what they say. I've been back to that school since, I hated it. So I don't really care.*
>
> *Kyson*

When practitioners made such assumptions, young people felt invalidated and mistrustful.

Class, finance and private health care

Some participants we interviewed talked about the inequality faced by trans young people from working class or low-income families when accessing healthcare services (see also *Accessing services and barriers* and cultural/social capital in *Power imbalances*). People of colour participants were often disproportionately affected by this.

> *From my first supplier [of hormone treatment], it was about a little over £1,000 a year and so divided by 12 that's something like £80 a month, really expensive, a lot more than like a NHS prescription. But it's what you have to pay if you go private. It's that or wait years.*
>
> *Lucy*

> *I went onto Nebido [long acting testosterone injection] but the only problem with that was it was a hundred pounds each time. So that was obviously very costly for me, obviously being in and out of jobs, and like obviously it was one of those things where sometimes there was, I'd have to make the choice, either eat or, or get this. So obviously the hormones always obviously kind of, came first ... The problem*

> *was sort of having the money coming in, because obviously then I was experiencing, []difficulties in, in my job and you know I ended up leaving my job, so there's, there's times of unemployment and homeless, so obviously now trying to keep up with the payments for the hormones is a struggle.*
>
> *Tevon*

Participants often talked about the extensive costs of private health care as a 'last resort' rather than waiting years for a first appointment with NHS services.

> *I guess, the fact that I do come from like a working class family. And I'm not fully white. I guess, I don't know sometimes it does make me feel like I'm not like, I'm not, I don't know like in general it makes me feel like less, less valued as a person by the whole of society. But within healthcare like I know that the fact that you know, my family is on benefits, it does mean I'm not able to get private services for my transition. And it does mean I have to have like really long waiting times.*
>
> *Tarian*

Tarian talked about feeling 'less valued as a person by the whole of society' as a young trans person of colour from a working-class family.

> *I think something that's important is that there's a lot of associated costs with top surgery that people don't think about. So whether or not you're getting the surgery on public or private healthcare, and all the associated costs with that, there's like you have to buy a lot of stuff.*
>
> *Tai*

Other than private healthcare costs for surgery, participants talked about hidden costs of health care. Tai talked about having to buy additional equipment that supported them with their recovery from 'top surgery' (chest reduction surgery) such as cushions and ointments.

Power imbalances

Overall, many participants talked about the power imbalance between patient and professional in trans healthcare services. As discussed in *Accessing services and barriers*, a few young people had different levels of social and cultural capital/advantage through education and financial means which influenced/could disrupt such a power imbalance (e.g. Haydyn saying 'I know how to navigate a consultation. I know what I'm entitled to'). However, young people discussed how trans patients need, overall, more power over their own health care.

> *I think that healthcare professionals have a lot of power over their patients. I think, you know, and especially within like a trans context, the ability to you know approve or deny hormone therapy for example, or you know approve, like approval, deny your own identity as a person, your own experiences, and again like yeah that's from a trans context. It's also from just you know disability and illness context, right, of actually being able to just put in your notes like what the patient is experiencing isn't real, or it isn't what they think it is.*
>
> *Sharnaz*

> *We need, we need more involvement, we need more voice, we need more power, we need more horizontally organised things that are not hierarchical*
>
> *Diya*

Many participants talked about the need for more equitable healthcare services that afforded more power to patients in terms of navigating their own healthcare journey. Many intersectional barriers stop people accessing the care that they need such as race and disability.

> *I'm really aware of friends who are non-binary who've like had their treatment delayed because even if they give the like, some kind of like trans, non ideal trans non-binary, ideal non-binary narrative it's still like still, not, not enough for the GIC sometimes. It also just like a real frustration in that, in that it's really clear the GIC's don't want to give up their power over us. And yeah, and like if it's, in saying like oh like GP's could do this or this, I think part of the reason we're not going to get that isn't happening is because GIC's want to maintain their power as psychiatrists over us.*
>
> *Diya*

> *I went to school where everyone was entitled and like the more entitled you are the more you're gonna get people to acquiesce your demands … I don't think that's really quite right, you know, it means like people that are working class or from migrant backgrounds you don't have that kind of education or you don't speak in the same kind of accent. They kind of get patronised the way I got patronised the first time the first few times I went to my GP.*
>
> *Lin*

> *Certain things have been kind of de-pathologised, that to a degree that there's, there's still a degree of like the interactions that people of colour might have with other psychiatric, with other parts of mental health services, and other psychiatric services, might like negatively impact how you received trans healthcare.*
>
> *Diya*

In the next chapter, issues of power and autonomy are further explored.

Chapter 5 Findings from the young peoples' interviews

Knowledge, care and expertise

A common thread running throughout all interviews with participants was the lack of knowledge and expertise in health care on transgender lives, bodies and experiences. The quality of care provided by the NHS was hugely variable and uneven. A lack of knowledge and understanding could result in inappropriate questions and language being used in consultations with the young person – something also found in previous studies.[88] This was often coupled with the burden of having to educate their healthcare professional. Trans patients often found themselves having to act as their own practitioner and provide the healthcare knowledge and expertise themselves which resulted in a lack of trust in services and professionals. Our findings from the health professional interviews indicate that there were significant barriers to providing good-quality trans care, even for those who wish to work collaboratively (see *Chapter 6*). This is echoed in the literature where trust in such consultations is difficult to establish.[89]

Where healthcare knowledge was lacking from professionals and in the absence of reliable information, trans young people turned to their communities and networks for care and support. Young people appreciated learning from other trans peoples' stories and experiences. This was especially crucial amidst the current trans-hostile environment. Young people talked about how negative media coverage affected, not only their everyday lives but also impacted their healthcare experiences with professionals who sometimes relied on misinformation from prejudiced sources.

General practitioners, primary care and knowledge

General practitioners are often the first point of contact in healthcare services for a young trans person when exploring feelings about gender and potentially beginning a transition. In the current healthcare pathway it is the GPs responsibility to make a referral to the appropriate gender identity service and if necessary take part in a shared-care agreement with a gender service to prescribe hormone therapy.[90] This is together with providing general and standard health care for trans patients.

Participants talked about their experiences of seeking support from their GP for the first time as well as their general experiences of primary care. Overwhelmingly, participants talked about a distinct lack of knowledge across the board about trans healthcare pathways, trans bodies, lives and experiences.

> *I don't think he really knew anything at all, which I don't blame him for but his knowledge was non-existent I think really.*
>
> *Reagan*

> *She didn't know much about how the, the system worked and she didn't know about how the hormones would effect, and how the gender identity clinic would work about, about referring me and whatever. So other than understanding what the word trans meant, she didn't really know too much about it.*
>
> *Liam*

> *It was like, 'Okay, so what is the process like?' She had no clue what the process was like.*
>
> *Alexa*

General practitioners encountered often did not know about the impact and effects of hormone therapy, referral procedure or the process of GICs.

Shared care

A key area where knowledge was lacking for GPs was regarding shared care agreements. Shared care agreements work on the principle that there is communication and collaboration between a GP and specialist gender service (NHS or private) to provide joint care for patients. Shared care protocols are used widely in clinical practice, not just for those seeking gender specialist services.

> *I wish that GPs knew a little bit more about shared care as well, because that's the problem that a lot of people I know have run into where they've gone private to get hormones because it's so much faster. But obviously, then their GP's been confused and unwilling to do shared care between them and the private clinic that prescribed the hormones, which then leads to kind of drop in that patient's wellbeing.*
>
> *Lake*

Participants wanted GPs to learn more about 'shared care prescribing guidance'. Shared care procedures and guidance was a frequently mentioned topic in the interviews with many young people wanting GPs to work effectively with other (sometimes private) healthcare providers. Young people felt that they had only gone down this route because of desperately wanting to avoid waiting years for NHS specialist services. Some participants had experiences of being denied shared care at their GP surgery due to a lack of knowledge and training and lack of guidance from practice managers.

Training needs

Participants discussed what they felt to be the key training needs of GPs.

> *I just wish they had some training in understanding the process of the medical procedures that I need to go through or like people have to go through in terms of transition that would be helpful. And just the fact that trans people aren't like these like weird group of people that are on the edge of like society, just like trans people exist everywhere like it's okay to be trans and the first thing that you should be doing is supporting these people.*
>
> *Afi*

Many participants said training was needed in multiple areas of trans health care such as transition-related treatments, shared care procedures, sexual health, mental health and general well-being. Afi wanted GPs to understand that 'trans people exist everywhere'. Participants felt frustrated that GPs could 'quite easily' educate themselves:

> *it's annoying because ... as a GP the internet is right there ... you can just look, that's what we're all doing, we're all just looking stuff up, you know. We haven't been told this by like a general, like medical professional it's all been stuff that we've had to go out and research ourselves ... it's a little bit infuriating that a lot of GP's sort of play the whole naivety card like well, you know, I don't know about this, this is all so new and it's like there's been transgender people about for like hundreds of years ... there's something you can quite easily look into yourself ... just get a few terms right and just learn what people sort of want to get out of that. And like nine times out of ten if somebody is coming to you with sort of like gender queries, you know, they're questioning their gender you can just say to them would you like me to refer you to ... the clinic or there are trans groups about, like probably if there was more stuff in GP waiting rooms, you know, there's loads of stuff about, you know, like oh get help, you know, like prostate checked, you know, cancer screenings and stuff but there's not, I didn't see a single thing about being trans it's all very like not like hidden but it's not advertised, so I guess it's sort of this idea that, you know, that you're not gonna know a lot about it unless you research it yourself.*
>
> *Dante*

In many cases, participants wished that GPs would take the initiative to do their own research prior to seeing trans patients. However, young people feared that a lot of healthcare professionals would rely instead on misinformation in the media (see below).

Burden of research and education

People talked about having to conduct their own research and take it to their GP for their first appointment to help support a discussion about their gender identity and transition needs.

> *[G]oing to the GP, kind of armed with a plastic wallet full of information that I'd printed off because at the time I, so I'd had to research kind of which gender clinic that I wanted to be referred to, and I remember personally doing a lot of research into that, because I knew that waiting times were starting to creep up, so every, all the information that I accessed, I guess I did myself, and I did through, some of it through the NHS website, but definitely not all of it.*
>
> *Ted*

> *In terms of visiting GPs when it comes to visiting regarding gender issues or trans stuff I feel like I've always had to go in doing more of the explaining, so I can't go in and be like 'I have this problem help me,' it's more 'I have this problem and this is how I need to fix it, can you just please do this one thing for me so that I can access this service?'*
>
> *Gordon*

> *A lot of the times I find myself having to explain things to my GPs and my nurses that they really should know, but basically having to like educate them ... At the same time, they don't really want to hear it because they don't want to be told that they don't know what they're doing, but [the problem is] they don't know what they're doing. So it's a very frustrating experience and I quite often avoid just going to the GP with my actual health problems because I know that it's gonna become a debate about my gender identity.*
>
> *Sanjay*

In these situations, there was both often emotional as well as educational labour. There was the emotional labour of having to 'come out' to GPs and try and articulate their trans narrative in a way that a cisgender GP with little knowledge of trans identities would understand. These experiences resulted in a lack of trust in GPs and meant trans patients would often avoid consultations altogether. However, having prior knowledge of working with trans patients meant that common mistakes and incorrect language use or intrusive questions were avoided and could lead to more positive experiences.

Negotiating expertise and body autonomy

The meaning of the word 'expert' was discussed in participants' interviews. On the one hand, young people acknowledged that while they lacked the professional medical authority on making decisions about their health care, they were experts on their own bodies and making the correct decisions according to how they felt about it. This ignited a conflict between the need for an informed consent model when making decisions about treatment and the role of GPs and medical professionals.[91]

> *I'm not a medical expert but I am an expert in how my body is reacting to things or you know how I'm feeling.*
>
> *Sharnaz*

Young people felt they still looked to doctors for expertise:

> *It just feels, it feels like the whole thing about like you need to educate your GPs. It's like, well, I shouldn't. They should be good enough doctors to know [laughs] I am sorry. It feels a bit like I don't take much joy in having to construct my own transition. I want there to be a framework. I want there to be people who have some expertise. I feel like trans people, the whole thing about like trans people being experts of their own bodies. It's like, well yes, but I'm not an expert of my own liver function. I'm not an expert of my own like my own spermatozoa production. I'm not an expert of my sleep cycle and my muscle to body mass ratio and these things are things that I want. I want an endocrinologist to talk to me about or a GP who knows something about endocrinology.*
>
> *Sky*

Participants conveyed that their expertise had limits, but that they wanted their doctors to have educated themselves more thoroughly. What they also expected was to be able rely on and trust their doctors for standard medical care.

Managing tension

Participants described a tension in primary care consultations between speaking to someone in a position of authority and being themselves a knowledge provider in healthcare settings. Some participants feared that GPs and practitioners could become defensive not having enough knowledge on the subject particularly if their authority was questioned.

> *Most doctors I hope do realise that they have, they are like a person of authority and a lot of the time patients will take what they say as fact. And I feel like when it comes to trans care, that becomes a kind of a conflict, not intentionally but like a conflict in the sense of they're put in a spot they don't have knowledge, and that obviously puts them on the back foot, and makes them feel uncomfortable.*
>
> *Rani*

> *As a trans person you constantly have to convince healthcare professionals that you are trans and you have these experiences and you are essentially trying to convince someone who has never had anything close to the experiences that you have of your experiences … the scary part of being trans … is that you basically have to convince someone that what you know about yourself is true and like what I was saying before you know that maybe you have to lie about some things to do it. You wouldn't want a relationship with the healthcare professional where you were lying to them. While you know that what you are doing is the necessary thing.*
>
> *Sanjay*

Participants often felt health professionals needed 'convincing' that they were trans and that the experiences they had were 'real' and worthy of treatment and care. This corresponds to previous clinical research with trans patients needing 'real life experience' as a criterion for being granted treatment.[92] As explored in *Chapter 4* a part of this also led to participants conforming to expected or traditional trans narratives to get the care and treatment they needed.

Agency and power

Participants talked about how the dichotomy of expertise and authority in trans health care was compounded by different power relations between patient and professional. Young people sometimes described feeling empowered imparting knowledge about trans health care and educating their practitioner, but at the same time this could also change rapidly:

> *I think on [the] one hand you almost get used to speaking to professionals, so on, on one level you kind of get used to walking into a room, having already educated yourself a little bit, and knowing that you might be questioned a bit … as trans people you just get used to doing [it] every time you walk into a room with a healthcare professional in one. I think that being said though, it can be very easy then to go into a room with this sense of power, and this purpose, and to then be disempowered very quickly when that professional for whatever reason, … [is] not supporting you … then sometimes that's valid, and sometimes I think there is room for, for challenge, because as a patient you're the expert in terms of yourself, but you're not an expert when it comes to that, you know medication, and diagnoses all the time.*
>
> *Ted*

Participants described the conflict between feeling the 'expert in themselves' while having to rely on a medical diagnosis and opinion. This corresponds with the literature criticising the diagnostic model of transgender health care whereby healthcare professionals are given the authority on whether patients 'are "eligible" for health services based on a client's appearance or gender presentation'.[47] This led to some feeling exasperated especially when treatment was urgent.

> *It was quite unsettling to me that [the GP] didn't understand the immediate urgency in my needing to be on HRT [hormone replacement therapy] as a trans person with dysphoria, I don't think she understood like that it was like harmful to my mental health to be expected to wait three years to medically transition.*
>
> *Lin*

> *We are basically at the mercy of doctors. Often doctors that know less about your care than you do.*
>
> *Lucy*

> *I guess on the one hand there's like an anxiety about not being like taken, not being taken seriously in terms of like, so in that thing of like getting prescriptions filled or like getting, getting the right, actually I'd say that's the main one, like getting the right medication, or not getting fobbed off with like a different drug from what you're used to taking, that isn't like effective or doesn't agree with you in the same way.*
>
> *Diya*

There was a sense that many young people were 'at the mercy of doctors' trying to grapple with shifting power dynamics – the emotional energy, preparation and investment in these interactions was significant.

Searching for 'truths' and honesty

Young people we interviewed described the difficulties they found with getting information.

> *Going on [R]eddit and sort of going off the word of a complete stranger who I know nothing if they're telling the truth. But then also, potentially, it's very like relevant, anecdotal stuff that they've gone through it, they've done it. It's the tried and tested thing.*
>
> *Isla*

> *There's not enough information available in one place for people to know what's actually going on because I will hear one thing from one person and one thing from another. It's like what is the actual truth of, of the procedure?*
>
> *Tevon*

A number of participants described the varied ways they sourced information, relying on online sources and anecdotes from other trans people. Some talked about receiving conflicting information from multiple sources on medical procedures. It was difficult to identify the 'truth'. Young people stated that information from other trans people was likely to be more honest about waiting times and what you could *really* expect when getting a referral.

Lack of resources and geographical variation

Trans participants talked about the lack of resources that were available to them after receiving an initial referral from their GP and facing a very long waiting list for a first appointment.

> *[The gender clinics] know that this wait is ridiculous, but they don't offer you support. The least that they can do is offer you some sort of therapy or see, you know some sort of psychiatrist while you wait*
>
> *Devon*

Participants called for more 'trans-positive services' where trans people could be affirmed in the knowledge their practitioner was skilled and knowledgeable in trans health needs. Participants wanted their services to be trans-led and gender services to work with trans people.

> *We just need like more like trans positive services. It feels really alarming that there are only so few and they're mostly centred, like as in services where trans people can probably feel like comfortable in the sense that the people there getting the services are not going to fuck up. Or say something offensive and that there's only a few and they're located in like major cities, quite often quite far away from each other.*
>
> *Diya*

> *I think trans people should work in GIDS, or like talk with the therapists and tell them how trans people feel, because you know they're seeing all these transgender people and yet the rules are still, even if you're like twelve and you get on early blockers, you have to wait four years of your life for things to be changed and things like that. I think if trans people worked with GIDS they could give them more of an understanding of what it feels like and what trans people want and need.*
>
> *Lilah*

Participants commented how outside of large cities there was no localised support outside of these areas. Some young people felt that geographically they could not access services that were mostly concentrated in larger urban areas. Archie wanted trans young people to be able to access support groups wherever they lived, not just in 'pockets' of the country (see also below on support groups):

> *I'd like there to be more structured support nationwide because it feels very regional where you get support. I know London there's like all these different charities are based and there's some places in the North where there are pockets of communities, but it would be nice if there was like support across the whole country ... and that you could access a support group wherever you lived and that there was like established communities and resources.*
>
> *Archie*

Suggestions were made by participants for an integrated service in general practice, linking it to local community support groups and online information. Faster access to support was needed:

> *I know what I'd like to get – kind of things done faster. I know there is a reason why it does take such a long time, which I respect and understand. I know it's still quite a new area of research. But I would like there to be a bit more options, like more options available to help underage trans people kind of feel more comfortable in their own bodies faster, basically.*
>
> *Kilan*

> *I think [my GP] could have given me a lot more support with like resources. Like there's some local groups and stuff that she could have pointed me in the direction ... of like websites andit was quite like 'oh I don't*

> *know anything about this, I'll see you in two weeks' and I was kind of like reeling after that conversation … that was like such a big deal for me and she was kind of like okay right I don't know what to do with that.*
>
> *William*

Care and the community

With several failings in the healthcare system, participants talked about the huge source of strength and support found in other trans people when dealing with and experiencing their trans journey and healthcare pathways. Queer communities often provided a vital source of support. Being able to speak to other trans people, learning about what to expect first-hand and being able to share feelings was a crucial way of navigating this.

Participants talked about how they relied on and provided for their community in mutual and reciprocal ways. Youth groups were vital for navigating trans health care. Safe coordinated spaces where trans young people could meet with others to talk about transition related health care, support each other and give advice was hugely valuable for participants.

> *Having a youth space where we were trying to, I guess like we were all in maybe similar phases of, in terms of trying to navigate stuff at a certain age, in terms of trying to navigate trans healthcare … We were all at similar points in our like lives or at a similar age in terms of trying to navigate trans healthcare, in relation to transition, and that was really helpful and in terms of like supporting each other and like giving advice.*
>
> *Diya*

> *It's almost like you almost befriend other trans people purely because you want to know, get the answer to questions that you're not getting.*
>
> *Dante*

> *I then attended a mental health support group but it was run as more of a youth group than sort of traditional sort of mental health support which was really useful. Just getting to hang out with people who had like similar experiences and this was where I had the support in terms of like, researching and finding out about gender services.*
>
> *Gordon*

Young trans patients said they preferred to trust the experiences of other trans people rather than (cisgender) healthcare professionals.

Community-based health care and 'mutual aid'

Participants wanted to see improved access to health care and treatment through their communities. With significant barriers to NHS and private care some participant sought to self-medicate. Some participants sourced localised knowledge in this way.

> *[Support comes from] other trans people. That's it. No psychiatrist that I've ever talked about feels comfortable discussing gender dysphoria with me. No GP. Yeah mutual aid, other trans people. It's where it all comes from.*
>
> *Haydyn*

> *Through apps, you know, I've been in contact with a trans girl in Ireland, who I've helped to get HRT.*
>
> *Haydyn*

> *I get my, like I self-inject T, but I just order my T and order my needles and things from friends or friends of friends, and so I've never, even though I'm kind of like medically trans [laughs]. I've never interacted with a GP about that. And that is because of some of the stuff I said before around particularly if you don't want to kind of be binary, it's never been a very supportive hospitable service and I have enough trans friends and have heard enough of their stories to kind of know that is true.*
>
> *Tai*

> *A friend helped me out and gave me some money to go to get my hormones going forward.*
>
> *Tevon*

Participants talked about 'mutual aid' as a way of supporting other trans people in their communities. Connections were made online through social networking, communities and forums. Others sourced hormones directly from members of the community sharing hormones. For some of those trying to pay the costs for private surgery, this meant setting up crowd funding accounts and help raise the money from other trans people.

> *Like the reason I've chosen to go private with medical care and stuff is because I know that I will be sitting waiting for a long time and I know the things that I will have to compromise. And I know the damage that it'll do to my mental health to go through the way that I've seen so many people go through the NHS service. And I'm, it'll kill me, and I know it will. Like I don't think I can do that myself, so I appreciate being able to be in a position of internet and communicating with people about this kind of stuff because I can go on websites like Go fund me and yes it's been sat there for months and months and months, and I'm asking for a few people to engage with me for a little while, but people are, and it means the world, do you know what I mean? Cos I gonna be able to get something that I really didn't think was gonna happen.*
>
> *Maddox*

Solidarity and support

As well as sourcing information and hormone therapy through their communities, trans people relied on their community for strength in coping with a hostile environment in the UK.

> *I think trans people are just trying like so hard to survive in the political climate. And so live under the kind of GRA [Gender Recognition Act] consultation and the rise in transphobic feminism, and the media's kind of attack on trans people. I think that, I mean partly like there's lots of trans people who don't have [a] physical trans community and so they're looking for other trans people online and there's nobody else to talk about how scared you are, or how angry you are with them, so online space has become the space for that. And it's so present that I think it's just taken over as a more primary need in those spaces, than the kind of more healthcare or community care aspects of wider care.*
>
> *Tai*

Participants also described collective goals for health care, which included gender recognition reform, better NHS provisions for trans people, as well as decriminalising sex work. There was strength and hope in coming together as a community to advocate for better health care.

Learning from others

Engaging with the other trans people was viewed as vital for supporting mental health as well as getting information about healthcare options and experiences. It made young people feel as though they were not alone in what they were experiencing.

Participants talked about finding information from charities like Mermaids, as well as online sources like Reddit, Tumblr, Facebook groups, Twitter and Instagram.

> *A lot of that information I got second-hand from people I knew, people on the internet, and it wasn't from, it wasn't really from the healthcare professionals themselves.*
>
> *Ted*

> *I use social media platforms as ways to access information from, you know whether it's organisations or whether it's reading other people's experiences, and stuff like that. I've used Instagram as a way of talking about my experiences.*
>
> *Oakley*

> *I browse sub-Reddits and forums and I'm part of the university trans group which is for sharing resources and information sharing ... I personally tried to, you know, advertise a sexual health services, giving lifts to people, ... and getting involved with my wider community.*
>
> *Haydyn*

> *I joined quite a lot of forums on Reddit and they were actually really useful and it was like you're actually talking to real people that, that have the same experience as you and they can come out with. So you can have the weirdest feelings about things and think you're absolutely crazy but then someone on there will have the same feeling and you're like oh [laughter].*
>
> *Eaton*

Participants were glad to find accounts of other trans people. They benefitted from engaging and connecting with their communities through online networks and sharing their healthcare journeys. Information from official sources was not felt to be detailed enough with more useful knowledge gained from online forums.

> *I had no idea sort of how someone medically transitioned and things and I went on the NHS website and stuff and like it wasn't very useful. I don't think, 'cos it was quite clinical in the way they sort of spoke about things and there was no clear path on what to do and how to get there. And it's never sort of explained to you how to actually approach the, the whole situation of going to your GP and bringing up the conversation. So I actually learnt quite a bit about that sort of side of things from like friends that were online and things and just like different forums and things.*
>
> *Eaton*

> *A lot of it was just me reading through whatever medical journals I could find, online. The most useful stuff that I found was other people's first-hand experiences. More so than anything on the NHS website or anything that I heard from a doctor was just, you know, reading what other people had to say and what it's like to be on hormones, physically and mentally, that sort of thing. That was helpful for me because, you know, no doctor has really known a lot about it that I've ever seen. Yeah, I think that the biggest and best resource out there is just other people at the moment.*
>
> *Kyle*

Relating to others

Participants described why such support was valuable. Feeling less alone and being able to relate to other trans people's stories was gained from online communities.

> *I think it was always really useful for me to meet other young people who are in similar situations because it really showed me that I wasn't alone. And also gave learning opportunities for me and for others being able to see like people who started going to a trans youth group. When I was like first coming out and seeing people who are like on hormones or who have like accessed medical services and like people who are where I wanted to be was really useful.*
>
> *Gordon*

> *[talking to trans people] can be very support, supportive. They can be very resourceful. I have often gotten answers when I needed them for specific questions … Quite often it's a lot better than what you can find online, to be honest or what you can find out from your healthcare professionals.*
>
> *Sanjay*

Young people said that finding a connection with others gave them a sense of hope.

Role models

For those that were just embarking on their healthcare journey, making connections with (older) trans people further along their transition was a useful form of support, and provided a role model or as Laverne Cox has spoken about, a 'possibility model'.[93,94]

> *I think just like having a connection with an older trans person who's been through everything like a message and have like support from if I needed it.*
>
> *Mason*

> *I think it was being able to see older trans people existing like just sort of going about their lives in like doing their thing and having jobs and families and like just sort of being there. Because it was so hard when I was first coming out to see myself as anything other than this like terrified 15-year-old who didn't quite fit in anywhere and wasn't quite male or female and didn't really understand anything that was going on and was trying so hard to work out what I wanted. And seeing people who are older who had done this and where able to like talk about the experiences they'd been through but where like living was really like important.*
>
> *Gordon*

It was valuable for participants to see examples of trans people living their lives and surviving. Gordon valued connecting with older trans people to talk about their experiences. Role/possibility models in the trans community were often looked up to. For TPOC, having a role model was vital. For Afi, it 'allowed me to see myself if the trans community' rather than feel 'like an outcast':

> *Seeing a black trans masculine person allowed me to see myself in the trans community … Following a lot of black trans masculine people on like Instagram has been like massive and just watching them live their life, it allows you to feel not like an outcast, it allows you to feel like a part of something, it allows you to feel as, not as hard on yourself and as like ostracised because it's so easy to feel ostracised within your community … Learning about it through like the internet and seeing a lot of representation especially of black trans feminine people or trans women and just like looking at their experience and just thinking like yo this is lit like how, I just was like you're, you living in your truth like that's, that's a really beautiful thing.*
>
> *Afi*

Experiences of hormone therapy and surgery

A valuable source of information and support from other trans people was learning about their experiences of hormone therapy. Participants described reading and watching online videos of young people talk about the physical effects of hormones, as well as guidance on how to access hormone therapy.

> *People sharing [the experience and physical changes of testosterone] because a lot of people think like I thought at the start that you start testosterone and like the next week you have everything you want, it's not like that at all and I think that's a big misconception as well.*
>
> *Mason*

> *[I was] very well informed before I even stepped like one foot near an oestrogen tablet. So, I knew exactly what to expect and I think reading testimonials as well from other trans people meant that it's like I*

> *tempered my expectations and I knew not to expect anything too fast on any of the results can vary quite wildly.*
>
> *Lucy*

> *I do have a friend who has been through it … So he's been through it and he, I have asked him a few questions about what it's like and you do get into the [GIDS] and you have your meeting and everything. I also have a friend who has just started their oestrogen patches so she's a trans girl and she's just started her oestrogen patches, privately … she says the effects do take a bit longer than she expected them to. So I do have some people who I can openly ask questions to if I need to, which is quite good.*
>
> *Kilan*

Others were interested in surgery results – particularly how other's bodies changed:

> *I think mainly for me I think it's sort of like looking at people's, their surgery results on their chest and how their bodies have changed. Because that's sort of what you want to look for, cause … you sort of envision how your body will change if you do decide to go on that journey.*
>
> *Dante*

Support with hormone therapy was especially appreciated by trans people who could not access services in a timely manner and had decided to self-medicate. Others felt they could not trust NHS gender specialists' recommendations because their guidance felt 'too conservative'. At the same time, participants felt that information from the internet from 'random people' also needed fact checking:

> *You go online and you're like, how do my results look? Some people are like great. Some people like no they're crap, you want these levels, you need to talk to swap to this. No, some people are like no you want to try this medicine instead. It's all like coming from random people at the end of the day you don't really know. You have to do a lot of like the sourcing and fact checking yourself. But, yeah, it's, I suppose the thing is, it's just it's not very credible, a lot of it. So, you are taking people's word for it, strangers.*
>
> *Isla*

Isla talked about getting support with endocrinology through online networks while self-medicating. This meant posting blood levels online to engage with other trans people about what levels of oestrogen and testosterone she should have as she went through treatment.

Meeting the needs of the community

Young people gave their opinions on how healthcare provision could shift to have more of a focus on engaging with trans communities as well as aiming to bring trans people together. While some participants talked about the huge benefit of connecting with other people online, especially during the coronavirus pandemic, others talked about the importance for trans people being able to get together 'in real life'.

> *With [c]oronavirus, it's like those online spaces are really valuable…, but they're not always … going to fulfil all of our needs. I'm really aware that like, really aware that like it's when I've like encountered the forms of community that I needed IRL [in real life], that even if I met those people via the internet. That was the moments where like things kind of started making sense, especially on the stuff that's to do with our bodies, and our bodies in space, or in a space.*
>
> *Diya*

> *I: What do you wish your GP, or GPs in general understood or knew more about?*
> *R: More about the issues we're facing as a community, in the trans community, what are the issues ideally to do with sexual wellbeing, to do with health well-being. To do with just in general the community and*

> *what it's all about or what is the issues underlying the community, just not necessarily about the sexual health element like making opinions on that basis but just more about the community, like, what we are and what we bring, how our lives are, our working ethics and, you know, as a community like.*
>
> *Aroofa*

> *I think for the trans community more information needs ... more about loneliness, more about mental health ... support groups within a network, more about the resources and then focusing primarily on the community more.*
>
> *Aroofa*

Young people wanted to see a comprehensive and holistic healthcare service at the community level that was focused on the diversity of that community, providing healthcare support and information to a large number of trans people.

Empathy, health care and the media

As discussed earlier in the chapter, many participants had experiences of poor health care due to healthcare professional's lack of knowledge and training. Another key factor that had a negative influence was the impact of misinformation and negative media coverage. Participants talked about how a climate of trans hostility or scepticism contributed to a lack of empathy and understanding surrounding trans people's health and left healthcare professionals 'wilfully misinformed'. Participants felt that work was needed within the healthcare sector to cultivate a culture of empathy and solidarity towards trans people with a role for the NHS to proactively challenge misinformation and prejudice.

The media, misinformation and discrimination

All trans participants talked about the negative impact that transphobia in the media and misinformation in society had on their well-being and their health. Many participants were angry, upset and frustrated at being 'debated' in public narratives. They said that mainstream media channels were 'right wing' and trans exclusionary feminists and groups associated with 'TERF-ism' (trans-exclusionary radical feminism) spread misinformation – these were seen as 'the voice of a few spreading negative messages'. It was frustrating when their lives (and medical care) were 'sensationalised' leading to 'dangerous fearmongering'. Participants stated how trans hostility negatively impacted their relationships with friends, co-workers, and professionals.

> *I feel like the media has a lot to answer for ... the media has not only kind of stoked the flames really, in terms of kind of framing people's opinions on gender, I think it's also, it's changed our relationship [with co-worker] really. Had [my work colleague] not fallen into that whole thing of reading media articles and kind of a very specific portion of the media, and how they chose to represent trans people, I feel like we may have had conversations and it may not have got to the point where that person is now very fixed in their view, and now every time the media chooses to cover something that's supported under critical point of view that person is again sharing things, and is, it almost affirms the way that they think. And it's really really, again, exhausting having to manage that ... there's only so much that you can read before it becomes subjective and before it starts really hitting you on an emotional level. Because the people writing these articles often aren't trans. Even the supportive ones often aren't trans and that, I don't; I think there's a lack of sensitivity and a lack of empathy with, you know when, when we're, we're talking about people's lives and at the end of the day when I'm reading it, you know at goodness knows what time, that's, they're talking about my life, and they're talking about the life of, of my trans friends. Particularly my trans friends that are transfeminine and have to navigate those spaces, that's something that's, that I think people forget, and yeah, I just think the media has a lot to answer for really.*
>
> *Ted*

Participants felt that misinformation in the media influenced healthcare professionals. Kyle describes how negative media coverage of trans health care influenced his doctor refusing his treatment. Detransition articles were influential to decision-making:

> *[GP] said that the doctors had been reading articles on the BBC and places like that about detransitioners. They had then decided for me that I might change my mind and they didn't want that. So, that was why they decided not to prescribe. That was one of the main reasons. It was just awful to hear because I am like surely, it's my decision whether or not I'm gonna change my mind. That's my choice to make … It's so biased and I just felt like, you know, well done BBC … Every time I see those articles about detransitioners, I know exactly what that's trying to do. I just didn't expect it to happen to me. It was rough to be honest.*
>
> *Kyle*

One of the consequences of misinformation was that it cast doubt in the mind of healthcare professionals on the autonomy and agency of their young patients and their capabilities to make important decisions regarding health care. Lake said their healthcare professional's misinformation led to them not taking the steps to making a referral.

> *There was a lot of trying to talk me out of it or kind of talk me out of a referral and the things that I wanted out of a referral … there were some [doctors who were] kind of almost wilfully misinformed.*
>
> *Lake*

For both Kyle and Lake, misinformation influencing the healthcare professional led to treatment/care being withheld. Young people were angry that some journalists were unethical when reporting on puberty blockers – prejudiced stories about a young child obtaining puberty blockers were completely at odds with participants' own experiences. The idea that treatment was being 'rushed' did not match their experiences. Fearmongering and lying were seen as directly promoting 'horrific views on trans people' and influencing suicide rates amongst young people. Further, it was felt that, while there was the rare occasion of positive media reporting, trans people were generally reported in medical terms only reducing them to their 'genitalia or hormones'.

Transphobia in the media and misinformation was seen as cultivating a lack of empathy and understanding for trans people in healthcare settings. A lack of knowledge and 'wilful' ignorance meant that some participants were met with a lack of empathy and understanding that directly impacted their healthcare options. Lin said that rather than be empathetic about what was being discussed, his GP was 'patronising'.

> *I've brought [GP] pages of research to look at and, and just yeah printed out articles and stuff, me and [partner] went through the internet and yeah. Like yeah I think we brought in like sort of a couple sort of legitimate papers about yeah I really, really felt like I had to like educate her from the baseline, she just literally had obviously didn't ever work with a trans person before and, you know, it would have been okay if she was a little bit more empathetic actually but she was incredibly patronising you know, it's not great.*
>
> *Lin*

Acknowledging gaps and appreciating honesty

Young people we spoke to appreciated caring and empathic practitioners that made the effort to understand and respect their healthcare needs. They also appreciated when GPs would honestly acknowledge their gaps in understanding and seek to rectify this.

> *When I've had GP's say to me, 'I hold my hands up, I don't know how this works,' I do appreciate that honesty, because if the GP is trying to do something that they don't know, and they don't know how it works it then causes delays, so I really appreciate them being honest with me about that, but then perhaps asking me how it works isn't the most appropriate thing either.*
>
> *Ted*

> *She sort of said that she didn't know anything about it and that could I come back another appointment when she knew more. So that was quite like anti-climactic. So I went away and she gave me a phone call and I went back and she said right I've got, I've referred you like they're gonna send you a letter and you fill that out and everything.*
>
> *William*

Participants described occasions where consultations with GPs were cancelled because they wanted to learn more about the topic first before giving advice and guidance. Participants preferred for their GP to be honest, as long as they sought to take action. However, even when practitioners were empathetic the structural barriers to knowledge and resources meant that many participants were mostly resigned to the reality that healthcare service were ill equipped to meet their needs.

> *My experience with my GP was just that she was empathetic but she just didn't know any of the practices and procedures ... in terms of mental health couldn't really do much, gave me like a leaflet and checked in when I went back how my mental health [was].*
>
> *Tai*

Building empathy and awareness

For many it was incredibly important that doctors were empathetic and sensitive, as this could make a huge difference to the clinical relationship. Young people were keen to suggest ways in which health professionals could build their capacity for empathy and understanding. These were often around tacit skills of learning better emotional awareness.

> *I think it's a two-way relationship where you can both work together collaboratively or work forward with it but I think even then you have empathy and understanding ... I was seen by the community mental health team. I was seen by a psychiatrist, two different psychiatrists at different times and I think one of the psychiatrists, she was ever so nice, she was a young lady, a girl and she had a way that she sympathised with you, the empathy, the way she talked to me, the way that she just came across ... I think empathy goes a long way but she was just I think just a human, and a professional who just loved her job and that was showing with the way she came across with patients.*
>
> *Aroofa*

More widely, participants felt health care could be improved for trans young people through collaboration and partnership. Participants also wanted to see healthcare professionals become advocates for better trans health care in their own right. Haydyn summed up the following recommendations for healthcare professionals:

> *Liaise with and refer to your local specialist, whether that's charities ... Please acknowledge the power that you have there and how scary and how much influence you have and how permissive or unpermissive your interactions with someone who is considering, maybe I'm trans or has decided they are trans and is engaging with healthcare as a trans person for the first time, how big that is ... accept the reality of self-medication and educate those and normalise the disclosure of that fact and how to go about that in a safer sense and advocate for trans healthcare as much as you can. Normalise general nonconformity and transness within your patient population.*
>
> *Haydyn*

Chapter 6 Findings from qualitative interviews with health professionals and parents and carers of young trans and gender-diverse people

In this chapter, we discuss the findings from our interviews with health professionals (*n* = 20) and then parents and carers of young trans and gender-diverse people (*n* = 19).

Findings from health professionals

Themes from the interviews with health professionals have previously been identified and summarised in a peer reviewed journal: Mikulak *et al.*[36]

The findings were summarised in four key domains: structural, educational, cultural and social, and technical barriers that faced health professionals in providing good-quality care for trans and gender-diverse young people. These domains are expanded on with further discussion below. Text in this chapter has been reproduced and adapted from the Mikulak *et al.*[36] This is an open access article distributed under the Creative Commons Attribution (CC BY 4.0) licence, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Systemic and structural barriers

As discussed in our paper,[36] structural barriers were identified such as shortage of services, long waiting times, lack of guidelines and lack of funding and support.[36] These structural issues compromised the quality of care that trans and gender-diverse people receive. Shortage of clinics was identified in relation to demand.

> *There [are] so few gender identity clinics around in this country … They simply cannot cope with the demand of the trans patients.*
>
> *Health professional, GP*

The resulting waiting times to access specialist services were frequently discussed. Some described it as at odds with the NHS commitment to provide timely access to specialist services:

> *The patient's charter says 18-weeks wait in England … we have now got to the stage where my local gender clinic is two and a half years wait.*
>
> *Counselling professional*

Delays in accessing mental health services were identified as an additional barrier to supporting trans and gender-diverse people. Further, lack of support and access to clear clinical guidelines for care pathways and treatment were identified, with some not knowing where to go to for help.

> *There seems to be a big void out there for managing these patients. It's all very much back to primary care. We [GPs] can't do anything. We are not allowed to initiate medications … We don't have the back-up. We don't have numbers that we can ring and say, 'help what would you do in this situation, please?' There is just nothing there.*
>
> *GP*

Health professionals raised questions about the lack of guidelines and one GP described her failed attempt to get more guidance:

> *I wrote to NICE [National Institute for Health and Care Excellence] … and I said, they have guidelines on everything … have you got any guidelines on the treatment of transgender people, 'no we haven't and we haven't got any plans to do in the immediate future.'*
>
> *GP*

Participants also emphasised that they were working with trans and gender-diverse people without clear guidance from local clinical commissioning groups. Health professionals also commented on the lack of support for patients while waiting for specialist services. In addition, participants recognised how huge waiting times pushed trans and gender-diverse people to use private care services, but this meant there was lack of support for GPs in managing any resulting shared care agreements.[36]

Models of health care

Health professionals reflected on the current models and pathways of health care, and some felt these could be too rigid. They discussed the approaches they took to trans identities and gender diversity and how it influenced their practice. The issues of trust, rapport and autonomy emerged. Some were keen to think holistically about young people's gender identity.

> *I think being able to be as holistic as possible in the given time to be able to support young people with all of the different needs they might have and what is a really crucial time in their lives, in anyone's lives as a young person, trans or cis. I think that 18–25 age bracket that I see is really when you are forming the person who you are going to be and you may have lots of different needs in regards to physical health, mental health*
>
> *Specialist registrar*

Health professionals felt it was key to work with the individual rather than apply rigid models of gender identity development automatically.

> *If one thinks about pathways … I think it's really, really important not to get confused over the many different models that exist and apply them without real consideration to the individual presentation.*
>
> *Psychiatrist*

There was a desire to open up the possibilities for gender to adapt and change throughout adolescence and adulthood.

> *Just because someone is a young person doesn't mean they can't have a really clear sense of identity, including if that identity is not strictly male or female. But actually there are a number of diverse gender identities for example non-binary, gender fluid, there are all kinds of things in between that are very fixed senses of identity.*
>
> *Specialist registrar*

> *I think one of the biggest barriers is the falling into the binary – the either/or thinking that oversimplifies the world. I think that whenever that happens it just closes down thinking and possibilities and options and risks; including a young person's options and choices for the future and their actual/current and potential/future opportunities.*
>
> *Psychiatrist*

However, some participants felt young people on the waiting list might be better served with general mental health support rather than specialist help. Some felt that exploration of other issues was important, and that this was a valuable model adopted at gender specialist services. This included general feelings about identity, body image, self-esteem.

> *I think many adolescents are coming here with wider issues than gender such as general self-esteem and identity issues, so it would be good to have something that is a bit less specialist … than our service first.*
>
> *Psychiatrist*

However, the approach of exploration to gender identity care was viewed by some as a move away from understanding and respecting the autonomy of young trans patients. Some health professionals viewed the exploration model as casting doubt on the ability of young patients to make concrete decisions regarding their treatment after having waited for many years. One health professional raised concerns about the lack of an informed consent model:

> *At the moment … we haven't got an informed consent model … we have got young trans people … telling the gender clinic what they think they want to hear, because very few young people feel able to go to the clinic and say, well actually, I don't know what I want to do … I have these feelings, but can I talk it through with you? Because they know that if they do that then they will delaying treatment by years.*
>
> *Counsellor*

As discussed in *Chapter 4*, this concurs with young peoples' experiences where some felt they needed to 'convince' health professionals of their trans identity or fit a particular expected narrative to receive treatment.

Negotiating the autonomy of young patients

Reflecting on these different approaches raised questions regarding the autonomy and agency of young people. One professional who worked within gender identity services felt:

> *I see it as my job as respecting someone's autonomy … trying to give them as global a view of things … to enable them to make … the best decisions for them.*
>
> *Specialist registrar*

Decision-making for some was based on questions of expertise, evidence and maturity (see *Chapters 5* and *6* for young people's views on expertise):

> *Respecting the young person as an autonomous decision maker. Meeting them at their developmental stage and respecting what they think. Also, providing them with counsel, like with, from our expertise, you know, this is somewhere they've come for consultation.*
>
> *Psychiatrist*

Participants discussed that young people mature physically and mentally at different ages during adolescence and this was something that needed to be taken into consideration:

> *The other thing is managing consent … if kids are going forward for physical treatment, managing consent for things that have a long term impact on fertility and bodies when kids are not fully developed and sometimes not mature enough.*
>
> *Psychiatrist*

Professionals also reflected on other health professional decision-making. The less a professional understood about trans identities or the journey a trans person might take, the more likely they would dismiss a young person.

> *I suppose depending on how much the healthcare professional understands the journey. One extreme they might decide this is something that they cannot talk about. They ... just completely dismiss the young person's wishes, because they are too young. ... I think ... that might happen and the young person feels completely let down or maybe never see another GP again.*
>
> *GP*

When coming to decisions about young people, it was important for doctors to learn more about the wider context of a young person, such as support they were getting.

> *I think it's important to respect a person's autonomy, but also to discuss with them ... how they have formed that sense of self and what their goals are.*
>
> *Specialist registrar*

> *I think that as a healthcare professional and also probably for other people, I think maybe they want to hear a bit more about how people make that sort of decision and what sort of support that young people get from their parents.*
>
> *GP*

Some healthcare professionals felt it was difficult for younger patients to be taken seriously in healthcare settings.

> *Young people are infantilised. We habitually undermine young people's knowledge and self experience and awareness. It's very, very hard for a young person to be taken seriously with the healthcare needs around trans issues ... I have seen 13 year olds ... treated as if they have absolutely no say and no autonomy. I find that really concerning, because I was a school counsellor ... working with teenagers. I think people underestimate the kinds of decisions that a 13 year old can make for themselves.*
>
> *Counsellor*

This was despite some feeling that that a young person's age did not necessarily make them any less capable about making important decisions about their health care:

> *Most of the young people that come to me have a very clear and established sense of who they are and what they want their goals to be.*
>
> *Specialist registrar*

Lack of education and training

As discussed in Mikulak *et al.*, lack of education and training was a significant issue for healthcare professionals.[36] It was a particularly pressing issue within primary care:

> *The first port of call [for trans people] is ... their GP ... think that is the biggest barrier there is ... GP education.*
>
> *GP*

All participants, especially GPs and nurses, thought that trans health was not sufficiently covered by their education and professional training:

> *I went through medical school ... there was nothing that I can remember at all on trans identities and health care for trans people.*
>
> *Oncologist*

> *In medical school there was no information or education [on trans health].*
>
> *GP*

> *Whilst I was training to become a nurse there was absolutely nothing about transgender health care.*
>
> *Practice nurse*

Part of educational barriers was not being aware of local resources to signpost to patients.[36]

> *If you don't know the resources locally then you cannot signpost people to the right places and so in, in our area we've got some fantastic community resources. But, you know, in my practice probably maybe three or four of us know them and would be able to signpost.*
>
> *GP*

Negotiating risk

One of the consequences of a lack of education and training for health professionals meant that some said agreeing to treatment felt like 'taking a risk':

> *A lot of GPs [locally] don't feel comfortable to enter into a shared care prescribing arrangement for a variety of reasons. Mainly ... because they haven't had.any training in this area so they feel that this is a specialised area starting hormones, particularly the initiation of treatments.*
>
> *GP*

Participants described how trans health care felt beyond their expertise as a 'specialised area' with little training or awareness. Unfamiliarity with non-binary identities also influenced decision-making.

> *Very often we don't initiate prescribing ... because we.. just don't have the expertise yet to do that. It sometimes can be quite difficult, because some of them are non-binary. They don't want some of the side effects, but they only want some of the other side effects. It's very tricky and can be also dangerous if you start doing all these prescribing prescriptions without knowing a lot about it.*
>
> *GP*

> *It might be an ideological objection. I think that's less often. I think it's more about lack of confidence or awareness...*
>
> *Psychiatrist*

Participants were keen to point out that being uncomfortable with prescribing did not come down to being unsupportive of trans and gender-diverse people but was an issue with feeling unsupported by their practice and practice managers.

> *We have had diversions of opinions in our practice. Some GPs, usually the younger ones don't want to do it. ... They are sympathetic, but they just don't want to take any risks because they are not used to it or they don't have any sort of care plans*
>
> *GP*

> *[T]here are some really genuine reasons ... why GPs are just struggling with this ... it's something that is imposed upon them. It's their duty of care and actually GPs are saying yes, but I absolutely don't feel safe. I don't know what I am doing. I don't feel I have adequate training or support. It's work that I am going to have to do for free and it's not covered on my contract.*
>
> *GP*

Such fears included not having sufficient knowledge about the drugs being used for treatment, where the young person was in their development, and the impact on their body.

> *I think it's about just understanding what happens to young people's bodies and what the drugs do and what they don't do. And also what is legitimate and what is right for the doctor to be involved in.*
>
> *GP*

> *There are things around prescribing hormones or endorsing surgeries where it's about someone needing to prescribe safely… and me not prescribing in a situation which I feel is unsafe which is going to damage that person's physical or mental health so that is where a kind of a line is … I see my role as supporting someone with their transition and trying to provide as many services to improve their physical and mental wellbeing … without doing anything that's going to do any harm in any way.*
>
> *Specialist registrar*

However, some health professionals debated the ethical positions of not treating trans patients.

> *But doctors are scared. They are scared of doing the wrong thing. What … they should be more scared of is doing the wrong thing, which is not supporting trans young people. And by not supporting trans young people, it's not a neutral option. Not giving them medical intervention and care doesn't do nothing. It allows that person to go through puberty, which is the most distressing and irreversible thing that can happen*
>
> *GP*

Cultural and social issues

A key factor that we identified in Mikulak *et al.* was cultural and social attitudes towards trans people.[36]

> *Some GPs will be actively against it and say that trans is not a real thing and the NHS shouldn't be funding trans care.*
>
> *GP*

A counsellor remarked how negative attitudes create discomfort:

> *I don't think they [GPs] really know how to deal with their own prejudice around this [trans healthcare] and that it's making them face something that they feel uncomfortable with.*
>
> *Counsellor*

Some participants felt that non-binary gender identities posed a particular challenge for health professionals:

> *I think it becomes sort of difficult for sort of health professionals to understand sometimes the non-binary. I think because it's easier for health professionals to think in [terms of] masculine/feminine.*
>
> *GP*

A therapist, who identified as non-binary, thought that negative attitudes more generally reflected conservative ideas about gender in society:

> *I think there are still a lot of misunderstanding around non-binary issues and … conservative ideas about gender [as binary].*
>
> *Therapist*

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.[36] This significantly affected the care provided:

> *I think that terminology and language is poor. I think GPs grapple and struggle just to really understand conversations around [gender] identity … [including the] use of pronouns.*
>
> *GP*

The use of singular 'they' (for pronouns) was identified as a particular challenge:

> *I think the most difficult for professional people, I think is them/their/theirs because it goes, I suppose it goes against your English education.*
>
> *Mental health practitioner*

Working with families

Health professionals described how cultural and social attitudes in society contributed to parental attitudes, and this presented difficulties when working with families. Participants spoke about parents of trans young people that were not likely to come forward for help.

> *The sad thing is that parents that we see are going to be the supportive parents, because they are the ones that bring their children forward for help. The ones that we don't see are the ones where the families are not supportive and they don't respect that child's gender identity or their gender feelings … We don't see them, which is a real shame. That goes back to the lack of education in society.*
>
> *GP*

For professionals working in gender identity services, they felt that much of the early work they did with young people involved providing knowledge and understand family dynamics:

> *I think the other really important thing within the first meeting would be an understanding of the perspectives, and the differences and similarities between family members.*
>
> *Psychiatrist*

Participants also spoke about the challenges of navigating health care for young people when parents and families were not in agreement with each other:

> *[Something] quite challenging would be where one person in the room is very keen to talk about … physical interventions for example, and another person absolutely cannot or does not wish that to happen … it's where there are strongly held views that seem quite oppositional and paradoxical. We then need to navigate through those.*
>
> *Psychiatrist*

> *It's when parents are not supportive then you sort of feel as though you are the middle of a family feud.*
>
> *GP*

Despite these obstacles, supporting a family to come together on a decision that supported their child was viewed as most important:

> *It's supporting parents as well, because … there is often a difference in what parents can manage or are ready for and what the child wants as well. I think it's helping support families come together*
>
> *Psychiatrist*

Technical and administrative issues

The final domain identified in Mikulak *et al.* included the technical and administrative issues that health professionals faced in providing good-quality care.[36] Inflexible computer systems with no options to record the gender a person identifies with as well as their natal one.

> *I did an audit of a cohort of trans people. When it came to whether their name on the clinical system and their gender marker ... reflected their gender marker and name in real life. Then only 50% had alignment.*
>
> *GP*

Inflexible computer systems were said to lead to both misgendering and exclusion from necessary check-ups and scans, with smear tests for people who have cervixes a common example:

> *After a patient has transitioned ... because their name and their gender changes on the system records. They don't get alerts ... understandably, they don't want to acknowledge that they might need a smear.*
>
> *GP*

Physical spaces, such as waiting areas in GP surgeries and reception areas, were also discussed as important to how trans and gender-diverse people felt – this included things like the lack of signs, leaflets and posters aimed at trans people. Some thought that such spaces were not set up to accommodate trans and gender-diverse people as they often were designed around a binary understanding of gender or were not seen as welcoming. Health professionals also raised issues of single-sex toilets and hospital wards as being problematic.

Findings from parents and carers

Next, our research shows that parents of trans or gender-diverse children face many pressures and challenges in health care.[72] These include accessing specialist gender identity services, being on the long waiting list, making sure their children are supported at school and looking after relationships with other family members. It can also be hard to find reliable information and navigate the healthcare system to get timely mental health support. As a result, parents often feel they are alone.

These findings can be grouped into three broad categories:

- participants' identified barriers to good-quality care for young trans and gender-diverse people and their families;
- support needs of families of young trans or gender-diverse people; and
- information needs of families of young trans or gender-diverse people.

Barriers to health care

Barriers to health care for young trans and gender-diverse people and their families was a strong theme that emerged from the interviews. Lack of knowledge of trans identities and gender-affirming care, and lack of experience on the part of health professionals were identified as a barrier to providing good-quality care outside specialist gender identity services. In the context of specialist services, insufficient provision and the resulting long waiting times, as well as lack of clarity around the protocols and 'gate-keeping' of gender-affirming care were the main issues identified.

Barriers within primary health care and Child and Adolescent Mental Health Services

Participants reported mixed experiences with GPs, CAMHS and other health professionals that ranged from supportive to outright negative and discriminatory. There was a sense that overall, health professionals lacked training and experience in supporting trans and gender-diverse young people and their families. Negative and discriminatory attitudes on the part of healthcare providers further complicated access and negatively affected experiences of the families.

Existing literature points to educational gaps in healthcare professionals when it comes to trans health, experience and identities.[34,95,96] This is echoed in our findings. Lack of knowledge and training in trans issues and health on the part of primary healthcare practitioners was a concern brought up by many parents.

> *GPs don't understand. They have very little understanding of gender dysphoria and trans kids... I don't think they cover it much in their education, although I think probably they will be in the future. But our GPs didn't really know much at all about it.*
>
> *Parent*

General practitioners' lack of training and experience, when combined with prejudice resulted in highly negative experiences for parents and carers of young trans and gender-diverse people:

> *It's really hard ... to articulate. But it's the way they [GPs] look at us. [erm] And the tone of voice that they use and the look in their eyes ... it might sound daft, but actually to be sitting there under the kind of gaze that almost feels like it's bordering on ridicule is very very uncomfortable. [erm] ... the first GP you know, very nice, soft voice and everything, but you could just see in his eyes it was just, it was not something that he was comfortable with at all. You know, he was keen to make the referral and just kind of get us out of there. And was keen not to really have ... any involvement in any kind of bridging care ... I think it comes from prejudice...I think a lot of these doctors don't have very much understanding of or have had much in the way of dealings with [transgender people].*
>
> *Parent*

Participants reported experiences within CAMHS suggesting that there is similar lack of awareness and training on trans issues and identities. One participant shared that her child's experiences with CAMHS was characterised by an assumption that being trans is a mental health issue:

> *It was always approached from a cisnormative perspective ... So it was an assumption that maybe it was a phase and he'd grow out of it. There was a perspective that the norm is to be cis ... So the perspective from the CAMHS team was, this was ... part of a mental health difficulty... But it just really felt as if ... this is a mental health difficulty, because you're trans, rather than actually the whole culture is creating a mental health difficulty.*
>
> *Parent*

In addition, the lack of capacity and funding within the services was a key issue for participants. Participants perceived CAMHS as overstretched and therefore only able to offer support to those in the most dire circumstances. One parent felt that the thresholds of who can get help from CAMHS is 'increasingly higher' and others thought that only children who were at high risk could access help and emphasised that young people have 'gotta be pretty suicidal to get CAMHS to take them on' (Parent).

Educational burdening, discrimination and refusal of care

In the context of health care, trans and gender-diverse adults are often burdened by the expectation that they will educate their healthcare professionals on issues pertaining to their health.[96] Our research suggests that this educational burden is often shifted to parents and carers. This is when parent and carers are supportive of a young person's transition. As explored in *Chapters 4* and *5*, young people, particularly those without parental support, take on this educational burden. Because healthcare professionals have significant educational gaps when it comes to trans health care and gender diversity, and also in terms of familiarity with the existing pathway, it is the parents and carers who often fill these gaps. Or, put another way, faced with inexperienced/uninformed and, at times, prejudiced health professionals, parents and carers might have no choice but to look for information and do research themselves. This creates an additional educational burden for parents and carers. As this parent put it: 'our experience is that you needed to do your own research to prove to the GP... what they needed to do. Felt like you had to make a case for referral'. This can be a barrier for people seeking a referral for their young person, as not everyone is equipped with the knowledge to guide their health professionals.

In primary care, the lack of knowledge and resulting challenges can be partially explained by lack of training among GPs. However, when combined with a trans-negative attitude, lack of knowledge leads to discrimination and in some cases refusal of care.

> *We also went to the GP and asked him to make a referral. That was an awful experience. He was quite obviously unsupportive of our difficulties. He told us that he wouldn't make the referral because the protocol was to refer to CAMHS. And CAMHS would then refer on if they diagnosed a gender identity disorder, which I knew to be incorrect. He wouldn't listen to me. So I then had to leave the doctor's surgery. My son said to me, 'He doesn't wanna help us, does he mummy?' And I said, 'I don't think he does today ... And then we had a battle with the GP to get the GP to make the referral'.*
>
> *Parent*

Worryingly, accessing support from the NHS sometimes was wholly dependent on the parents' knowledge (of referrals and rights) and determination. In other words, it was the parent/carer's cultural and social capital that influenced how much support was received:

> *We decided that we would ask the GP to do the referral to the specialist gender service. And the GP was not keen at all to do a referral and it was only because we A) knew that the service existed and B) we printed out the referral form ourselves and we literally kind of sat down with the GP and said, 'We have a right to this referral, here is the form.' We managed to get the GP to, very reluctantly do the referral. And but I think if we'd have been less educated about what services are out there ... the GP would have said, this isn't a thing we deal with.*
>
> *Parent*

This poses a sombre question of what happens to young people whose parents are unable and/or unwilling to not only get the information necessary to access help from the NHS, but who are also unable to challenge a health professional's refusal of care? A telling example comes from another participant who shared:

> *Eventually we managed to tell the ... [CAMHS] therapist and I knew that they were supposed to do a referral ... to the GIDS adolescent services, but I was told ... that they didn't handle things like that and we were just basically cut loose and left to float. It then took my daughter a great deal of time and soul searching to be able to then go to our GP, who has been extremely supportive, in order to then make the referral to the [GIDS]. By which time, the waiting list had doubled [sighs].*
>
> *Parent*

In the case above, the referral was delayed due to an unhelpful and misinformed response from CAMHS, leading to additional waiting time and distress for the young person and their family.

Finding supportive general practitioners

A common theme in the interviews has been the considerable time and energy parents and carers spent researching the best healthcare options including finding or changing their GP. Some parents felt they needed to change their child's GP, in particular if they had a negative experience with a specific individual or practice. This extra labour performed by parents and carers points to the prevalent trans-negative attitudes within primary care settings.

> *R: Our experience there has been good on the grounds that our GP was supportive. I read through Mermaids that a lot of GPs have no clue. So maybe they could do some education on gender issues. But in our personal case, we've had a very, very good GP. But again, it's down to research and before you register with a GP. If you've got a trans child, ask the questions before you register. And if you find that it's a transphobe running the surgery, go to a different surgery. You do have free will. You don't have to go to that one ...*
> *MM: What kind of questions would you ask a practice?*
> *R: Immediately mine was black and white: Have you dealt with any trans ... patients in the past. What's your stance on transitioning patients? Have you had any training in trans issues? Are we likely to get a good response?*
>
> *Parent*

While this parent framed his experience as one based on choice ('you do have free will'), what his experience illustrates is that lack of prejudice is not the *norm*, but rather something, that needs to be controlled for, through rigorous research. Consequently, and pointing to the same issue, positive experiences with GPs are often framed by participants in terms of 'being lucky', or 'fortunate', as opposed to being the expected standard. One participant said: 'I think fundamentally that we've been really fortunate that our GP ... the whole practice has been exceptionally supportive of us'.

Positive experiences with GPs were marked by their willingness to educate themselves but also to take on shared care and deliver elements of trans-specific health care, such as administering hormone blockers. For example, one participant shared

> *the GP's surgery were fantastic about administering blockers. And I know a lot of GPs won't do it ... They sent the practice nurse to have some special training, because ... you have to mix the injection... And they've always been fabulous about doing that ... I was really surprised when I learned from other parents that some doctors won't do it.*

However, our research highlights the highly uneven and variable access to care, where adequate support might be contingent on individual attitudes of healthcare providers, as opposed to an existing standard that would ensure equitable access for all.

Barriers within specialist care

Within the specialist gender identity services for children and adolescents, the following barriers were identified as most challenging for young trans and gender-diverse people and their families: insufficient provision of services and the resulting long waiting lists; lack of clarity about the protocol and processes, and gatekeeping of gender-affirming care; and the challenges in combining elements of private gender-affirming care with the care provided via the NHS.

Insufficient provision

Participants reported having mixed experiences with the GIDS (the GIDS service closure began from Spring 2023 with a move to a new provider model establishing regional services – see the NHS England website for more details), but many wanted more support and more engagement with the service. There was a strong sense that the NHS is not meeting the demand for gender identity services for young people, due to both lack of funding and lack of prioritising gender-affirming care. One participant observed that, 'funding is the obvious [issue]... there just are not enough practitioners. Waiting lists are too long. It's so difficult to get referrals so yeah, I think that's another big barrier'.

Related to the point of provision, many participants stressed the time and cost involved in getting to the appointments, which are only available at five locations across England and Wales, and the exceedingly long waiting times to be seen by a specialist (see more on this below). This cost is both material in terms of lost income and travel, but it is also emotional in that it puts a lot of pressure on the family and the young person:

> *To have to travel for well ... two hours in order to get to the session. The session is every four to six weeks and they tail off to less. It's difficult. Puts a lot of pressure on the young person to come up there and be forthcoming on that day. Something more locally accessible [would be better]... I really don't see without a massive injection of funding that the sessions could be brought closer to the individual.*
>
> *Parent*

Waiting time

The waiting times (during the writing of this report in 2022–3) to be seen by the GIDS often exceeded 2 years. A strong theme in the data was that the long waiting list to the specialist service negatively affected participants' children mental health, themselves and their families. The time spent on the waiting list was stressful for families, who also felt largely unsupported during that period. One parent noted 'so, the challenges have been the extraordinary long waiting lists to be seen by the Gender Identity Services for kids. We waited 20 months from the first referral through to our first appointment with them' Another parent shared:

> *I think it's terrible... I know two years when you're an adult doesn't seem like that long. But that's two years out of somebody's childhood... at the beginning of that time they could have not entered puberty. By the end of that time, you know, they could be having periods. They could have breasts. They could have a full beard ... it's really urgent that young people get seen and ... the level of anguish and distress... Our daughter was really, really ill. She was really unhappy. You know, I used to have to sleep on her bedroom floor at night, because she was frightened that she would get out and harm herself. And all that time, we were waiting for help.*
>
> *Parent*

While most parents we spoke to accepted the waiting time as something they could not do much about, a few spoke about challenging the waiting times with GPs. This usually came with considerable extra work, energy and labour on the part of the parent. On the other hand, one parent who did not accept his child's gender identity said he was 'very pro waiting list[s]' and said that 'fortunately, there's a massive waiting list there, so... hopefully... there's no rush to do anything.

For all parents, there was a sense that the time spent on the waiting list was characterised by complete lack of support from the NHS (see more on support needs below). During the wait, there was also very little communication with the specialist gender services, which was a source of additional stress for families.

> *During that wait, [on the] waiting list ... we heard nothing. There was no correspondence or no communication at all from the gender services of when we were gonna be seen ... we only got a letter to say we'd been accepted on the waiting list and the waiting list was currently 18 months. And we had nothing from them, personally, until we actually got the appointment letter through like 20 months later. So like, we were, we were left in the lurch not knowing when, if and when it was gonna happen ... What would have been useful would have been ... just a brief telephone call saying, you are on a waiting list.*
>
> *Parent*

Lack of clarity and gate keeping of gender-affirming care

Our data suggest that participants have very mixed experiences with the specialist gender identity services for children and adolescents. One view that was expressed by several participants was that the care received from the service varied depending on the clinicians. This was also compared with other country's clinical care:

> *I think it just varies depending on which consultant you get. And I have… read some articles by some of the GIDS clinician, which pointed towards transphobia, really. I think, yeah, transphobic ideas. I'm not sure that they are best placed sometimes to be an expert in the area, some of the people that work there. Judging by the experiences from different countries so I've seen lectures and things by clinicians from other countries who seem a bit more advanced than the service that we've got here.*
>
> *Parent*

> *Lots of different types of therapists that work under [the GIDS] umbrella. So there's no … standardised care. It really is a bit of a Russian Roulette in terms of who you get … I know that there's some therapists that are working in the [GIDS] that are actually ideologically opposed to the notion of trans kids getting any level of support.*
>
> *Parent*

When it comes to issues with care received, issues of gate keeping of gender-affirming interventions and lack of clarity about the assessment process and existing protocol were main points of critique. Several participants thought that the current pathway needed to be clearer; they wanted more transparency so that they could understand the process of going through gender specialist services. Having more clarity about the waiting times for particular interventions was also important: one parent stressed that it would allow their family to consider private care, without feeling that they are left 'on hold'.

> *We were trying to access oestrogen for [name of participant's daughter]. And we felt very much that we were caught up in a 'Catch 22' because she had to be sad enough that they diagnosed gender dysphoria. But then, they seemed to be saying that her mental health was too poor for her to be able to go onto hormone treatment. So it was kind of like, you had to be quite sad, but not too sad … You know, it was sort of like, oh well, I'm afraid you're actually.. distressed enough to have gender dysphoria so that's a tick, but now you're too distressed and so that means that your mental health isn't stable enough to access … we also picked up on a couple of other things with them, so this idea that in order to access hormones she would have to present in a more stereotypically feminine way. You know, we were just shocked that anybody would say that … And then the last thing was that they told us that they had a policy that someone has to be on blockers for.. a minimum of twelve months before they can access hormone treatment and they said that that's just a protocol. But then when I read the protocol, that's not what it says.*
>
> *Parent*

Negotiating the existing NHS protocols, the long waiting list and the young person's often-strong wishes to access gender-affirming interventions (e.g. puberty blockers) can be stressful for families. In our interviews, participants spoke about a sense of urgency to get their young person on hormone blockers or start hormone therapy. Some also emphasised that it was important for their child to access hormone therapy to stop their child's mental health from deteriorating. One participant said that their child was on 'a bit on the knife edge whether they would actually make it that far' (parent).

Moreover, several parents spoke about hormone therapy having a significant positive impact on their child's well-being. One participant said about her daughter: 'as soon as she was able to start taking oestrogen as well, you know, her physical health improved. She felt so much better. But more than that, she just feels … comfortable in herself now'. Similarly, another participant emphasised that for his child 'the fact that they're taking testosterone has eased a lot [of] the mental health stress'.

However, participants reported experiencing gate-keeping of these vital interventions on the part of the child and adolescent gender identity services.

> *One of the frustrating things around the whole NHS system and the specialists ... puberty blockers and cross sex hormones are provided and prescribed by GPs across the board for different reasons. So, ... they don't need to go to tertiary service. They need to go to a specialist service. In terms of the gender identity services, that they can't do that unless it goes through like a specialist provider ... And at the moment, because it's all tied in with mental health that this mental health screening bit needs to happen first before young people ... can be prescribed hormones or puberty blockers. And so there's like these levels of gate keeping. As time went on, the waiting list was getting longer and longer ... We didn't really know when we would be seen for our first appointment. We then knew that there was gonna be another six months at least of assessment before we got seen by the endocrinologist as part of the GIDS. I knew that if we didn't put things in place, my son wouldn't be alive.*
>
> *Parent*

Finally, young people who are neurodivergent can face additional challenges accessing gender-affirming care (see also *Chapter 4* about young people's experiences of autism and neurodiversity). One participant felt strongly that her daughter's neurodiversity worked against her in her dealings with the services. They found the format of the GIDS appointments and activities, where the young person is expected to talk about their feelings – something which autistic people might struggle with – was not well suited to neurodivergent people. For example, the young person was encouraged 'to join their [GIDS] young people's group… now she's neuro atypical, she doesn't like to chat. She doesn't want to talk about gender anyway. So she didn't want to do that'.

Private care and the National Health Service

Participants interviewed for this study sometimes opted to pay for private care for their child, in particular to alleviate deterioration in their child's mental health (see also *Chapter 4* on young people's experiences of private care in *Class, finance and private health care*). One parent shared:

> *I don't know what would have happened if we hadn't been in that position to be able to do that or I actually do have a fear that he probably wouldn't be here now if we hadn't accessed private treatment.*

This was, however, only an option for those parents or carers who could afford this. Those who opted for private gender-affirming care for their young person reported feeling judged negatively for this decision.

> *I needed to support what was best for him here and now and so looked at getting testosterone for him. But it was a lot of soul searching, particularly knowing that I was gonna be going against, what the NHS was doing. But there was loads of people out there that would criticise me..I've been called child abuser and awful things, And I knew that other people may not make that decision, but just, you know, the personal decision that I made ... with my child, 'cos my child was, you know, very intelligent and mature at sort of saying, that's what I wanted to do'*
>
> *Parent*

Those who could afford and opted for private care for their young person reported that this complicated their young person's care within the NHS. The NHS could, for instance, insist that a 12-month course of hormone blockers must be repeated before gender-affirming hormones could be given to the young person. In another case, a parent said that the NHS made it clear that they would not accept their child into their service as they had previously sought private care. Managing the relationship between a private healthcare provider and NHS could be difficult for families. One participant felt that even exploring private options for her young person was perceived negatively by the NHS and caused the family a lot of anguish:

> *I contacted our GP and talked to the private supplier of the hormones and they said they were happy to do shared care. I didn't realise that the hospital didn't do that and that they were going to drop us like a hot brick, because I wanted to, I spoke to the therapist and I wanted to talk it over ... at the hospital, but the therapist contacted the hospital and told them we'd done this. And [a] week or so before the hospital appointment [I] got a notification saying they were cancelling. And I didn't know where I was or what we were doing and I begged them to let us at least come up and talk about it and I said we would drop the private hormones if that meant we were kept on.*
>
> *Parent*

Accounts such as this point to a serious issue whereby families who access private gender-affirming care, often out of desperation and in the face of waiting times that exceed 2 years, might be penalised for their decisions.

Cisnormativity

Another barrier to health care for young trans and gender-diverse people and their families that was identified within NHS specialist gender services, was the cisnormative approach that participants felt was permeating the way the service operates. One participant referred to this as 'institutional cisnormativity'. This is particularly pressing, as it has some explanatory potential for thinking about the other issues raised (such as gate keeping of gender-affirming care and lack of clarity around the pathway).

> *I think the, the service is still set up to help protect cis kids from making a mistake. I don't think it's set up to make sure that trans kids have a great experience and that seems ... for me that's institutional cisnormativity ... And I've spoken to different clinicians who specifically said to me, 'oh you know, well, we've got like a thousand kids, but you know, if twenty regret it then we've failed'. And, and I'm I'm like well, … it's a more nuanced conversation anyway than just regret or not regret. But the fact that the service is most worried about the impact on a cis child who makes a mistake then they are on the impact on a trans kid who just wants to have a happy childhood ... that balance of what they see as their duty of care is, for me, a flawed balance. And I want them to see my child as an individual and say what would be in the best interest of this individual child. And that's the kind of healthcare that's followed in America, Canada, USA, Spain. It's a child centred healthcare where they, they look at what would be best for that specific child. And, and here, the protocols are very rigid and inflexible and it's still about the psychologist checking that their child knows their gender and checking that there aren't external forces forcing a child to pretend to be trans.*
>
> *Parent*

> *GIDS for instance, I don't think they've really taken on board what it means that the World Health Organization is saying that being trans is not a mental health problem. You know, it's such a fundamental thing, isn't it. But I just don't think they've really traced it through. So if we're saying it's a totally normal thing and just normal for human beings to be trans, what … are the actual implications of that? What does that actually mean? One of the things it means is that some children are trans, because, you know, if it, if it's natural for adults to be trans, well they don't just appear from nowhere.*
>
> *Parent*

The logical extension of such a cisnormative approach is an overemphasis of the possibility of cis-gendered children making mistakes. However, such emphasis is rooted in pathologising understandings of trans and gender-diverse identities and lives. For gender specialist services to be able to serve the population they are set up to serve, taking a gender-affirming approach and moving away from pathologising practices and views needs to be the bare minimum of good practice.

Support needs

Another strong theme identified from the data was the need for more targeted support. With prejudice towards trans and gender-diverse people and long waiting times for specialist services, supporting a trans or gender-diverse young person can be stressful for families.

> *In the first couple of years, it's a lot of work to advocate for your child ... there's the point in which the parent says, 'okay, I will accept my child as a girl', but then, there's suddenly the moment when you're like, 'oh, okay' and you kind of think of all the other people in your child's life which ... you know, swimming teacher, gym teachers. You know, there's a lot of people in their life, grandparents and doctor and you suddenly realise you've got to help your child like you've got to advocate for your child with all these people in her life ... it can be a lot of hostility from different individuals. And it's really, really emotionally hard work.*
>
> *Parent*

A young person's social and/or medical transition affects the whole family. From the data, there is an urgent need to provide support for parents and carers and the wider family of young trans and gender-diverse people who are on the waiting list. Parents felt that support within the NHS is practically non-existent for families and little is available from mental health services with participants creating their own support. One participant observed 'I don't think there's any support at the moment in the healthcare system... You would just have to make your own sort of support' The lack of support was described as a huge gap, as one participant put it, the lack of support for parents is 'the biggest kind of holes'. Another participant shared, 'it's not a whole lot [of support] out there. Not that I found and I *have* searched' (parent).

The waiting time was identified as the time when families support needs were particularly urgent, yet there was often no provision. One participant shared:

> *it was difficult when we were on the waiting list without support. Just desperately wanting to go through it. And at that point [my child] was going through puberty and that was creating an awful lot of stress. I didn't know where to go.*
>
> *Parent*

Besides personal support networks of friends and family, peer support groups and a handful of charities are the most important sources of support for parents and carers. The most prominent of these is *Mermaids*, a charity devoted to helping trans and gender-diverse children, young people and their families. The charity runs a helpline, offers online resources, arranges some local meet ups that bring families together, and runs online forums where families can connect with others in a similar situation. Most parents we talked to have engaged with Mermaids, either through online forums or via the phone helpline. Some participants felt that *Mermaids* was the only source of support for their family. For one participant, Mermaids was 'the entire support that we've got'. Those participants who had a local support group talked about the importance of being able to attend group meetings and events. The groups were a place for parents to share experiences, get information and advice, make friends and socialise. Support groups also offered an accepting environment free of judgment. For example, one participant explained 'I think they [parents] find it useful to go somewhere where they're not judged. They're accepted and there's someone there that understands what they're going through. It's really useful'.

Hillier and Torg suggest that support groups provide an important complement to clinical care for parents and carers of young trans and gender-diverse people.[97] In our data, we found that support groups provide much more than this. At the same time, our findings suggest that there is not enough signposting to these helpful support organisations from the NHS and gender identity services.

> *A lot of people are waiting for a really long time with no support and that's a key time to get the support in place and if GIDS recommend groups, charities like Mermaids then I think that's a way forward to help the*

> *parents and the children understand what's gonna be happening and what the next steps are. I do know that some parents have said that they've been to their appointments at GIDS and they've other families in the waiting room who have never heard of Mermaids. I don't think that should be the case at all.*
>
> *Parent*

Information needs

Information needs of families of trans and gender-diverse young people was another strong theme in the interviews with parents and carers. While participants reported feeling well informed about the different healthcare processes and options for their trans and gender-diverse young person, this was a result of their own efforts and sometimes extensive research. They therefore also spoke about the intensive labour of looking for and filtering through information, mainly online. Participants reported that there was a limited number of reliable sources of information that they felt they could turn to within the NHS, and many relied on a range of online sources and charities to educate themselves about the rights and healthcare pathway options for their child. Participants reported spending a lot of time looking for information, especially when they first found out that their child was trans or gender diverse. Looking for information could be a long and ongoing process, as one participant explained: 'it wasn't just a one off thing… it was over … days, weeks, months and continuing going back to it'. Participants often thought that there is not enough information on the official NHS and gender specialist services' websites. Some felt the information available from the official channels was too general and stressed that GIDS, in particular, should be more proactive in providing information to families.

> *When you get referred to GIDS then they should send you information, which they don't do at the moment, they just send you a letter saying you are on the waiting list and how long you are gonna wait. They should send you information about the process, what might happen. And also, they should send you information about support. Support is the most important thing. Support groups, if the healthcare system and the NHS can't provide that themselves, then they should point you in the direction of the support groups that can help you … while you are waiting.*
>
> *Parent*

Again, the charity *Mermaids* was identified by many participants as a valuable source of information:

> *The best information I had come from Mermaids … when I first contacted them they had… a sort of ready-made package of information that they sent to me. The reason why it was so helpful is because the remit was wide … So, it was sort of in organised in sections. It was available to me quickly, literally, I had it within a couple of hours. And it was helpful in that it signposted me to legislative provision to, you know, policy to, it was really, it was really helpful. And it gave me a really good head start in loads of different areas. And I could then take what I needed from that and develop my learning and read around whichever given subject matter was relevant to us at that time. There does tend to be a bit more information available now on the internet, but it's kind of watered down a little bit. It seemed, but compared to any other 'condition' for want of a better word that would be treated by the NHS there still is very little information, very little objective information available.*
>
> *Parent*

Participants also got information from talking to other families online. Many said that they particularly valued finding out about other people's experiences through online forums and support groups for parents and carers (see more on support groups below), such as the one run by *Mermaids*. The forums are a place where parents and carers can ask questions and get direct advice. Online forums provide practical information that many parents thought was less available from the official websites of GIDS and the NHS. Describing the *Mermaids* forum, one father said: 'all the information I needed was on the forums. I would ask and within 10 minutes, three or four people would reply'.

In addition, participants felt that their often-extensive knowledge was not valued within the healthcare system. This made parents and carers feel both disempowered and patronised (cited in Mikulak 2022, p. 66 reproduced under the Creative Commons Licence).[72]

> *I think that they [CAMHS] didn't realise that I had access to lots of different articles ... that I read all the time, because that's what I do. So I was far more informed than them and they were trying to basically teach me to suck eggs.*
>
> *Parent*

> *I think it's very important that GIDS practitioners actually think about what it means that families have been living with this for two years before they get seen. I've read quite a lot of [surnames of two people working at GIDS] work and they're so dismissive of parents' expertise. They talk repeatedly about, oh well, parents read things online and they think they know this and they think they know that. Well, yeah, I did read things online, they were peer review journal articles, where do they get their information from? Do you know what I mean? Just cause I found it online it doesn't mean it's stupid. And, and I think ... they don't take into account the fact that by the time they encounter a family with a trans child, that family probably knows more about it than they do. You know, after two years you certainly would be up to speed.*
>
> *Parent*

Misinformation

While participants reported having looked for information extensively, the quality of information was also raised as an important issue. Families' information needs are key in the context of the highly polarised public debate on trans children and health and the misinformation and pseudo-science that surrounds the topic.[98] Participants reported feeling that they had to work hard to find reliable information One participant explicitly expressed worrying about the effects of misinformation publicised by an anti-trans groups that is harmful for young trans and gender-diverse people:

> *There's a lot of work out there that looks legit ... There is a group of anti-trans adults out there who have created their own toolkits, basically saying, don't support the child in their preferred gender, keep 'em as their birth gender, you know, and it looks very professional. And the scary thing is, if schools access this they'll think it's the right thing to do.*
>
> *Parent*

Moreover, some participants pointed out that with so many different and at times conflicting sources of information online, it was easy to find something that reflected a person's own beliefs and views: 'It [the information you find] depends on your point of view as well [] people have different views on it'.

Timely access to accurate information is crucial. Given that parents can act to both facilitate *and* impede access to gender-affirming care, their unmet information needs or any misinformation that they internalise that is not effectively challenged might have negative consequences for their young person. It can lead to justify denial or delaying of gender-affirming care. An example of how misinformation affects gender-diverse and trans young people and their families is illustrated by a situation when a participant, who was explicit about being non-affirming of their child's gender identity, was convinced his child suffered from rapid-onset gender dysphoria (ROGD).

> *Rapid Onset Gender Dysphoria, which is posited as being a set dysphoria, primarily started through social contagion ... it's very very pronounced in girls ... Often presenting in early teens around puberty. Often following by an intense period on social media and also potentially triggered ... with other clusters of other kids transing [sic.] in the same schools and social circles. My daughter checks absolutely every one of those boxes. I do believe this is a, a social contagion cannot be ignored in here.*
>
> *Parent*

Rapid-onset gender dysphoria is not a diagnosis that exist in any medical or professional diagnostic manual and it has been dismissed as pseudo-science deployed to undermine advances in trans health and rights.[98,99] However, unlike organisations in for example Australia and the World Professional Organisation for Transgender Health, there has been no official denouncing of ROGD by professional bodies in the UK.[100,101] The above quoted parent was non-affirming of his child's gender identity and refused to support their social transition. In the context of how important parental support and acceptance are, this points to the urgent need to counter misinformation and pseudo-scientific claims about gender diversity.

Based on our research, it is clear that information and misinformation are key sites where the NHS is seen as not doing enough for trans people and their families. In recent years, public debate in the UK has been dominated by trans-hostile voices that call for rolling back of provision of health care and support. Parents and carers are negatively affected by this public debate that pathologises trans people and fuels moral panic around gender-affirming care (see also *Chapters 4* and *5* on young peoples' views on the media and misinformation). Health professionals and the NHS at large have a role to play in not only delivering timely, gender-affirming care but also in advocating for young trans and gender-diverse people and their families in the public sphere in the face of health misinformation and scaremongering. Many people interviewed felt that gender identity services were failing to champion the rights of trans and gender-diverse people.

> *It's like everybody's scared to stand up for the trans and the diverse young people. You know, the [GIDS] is the place to go for trans young people and [] gender diverse. But they don't ever stand up and say anything positive. You know, they never stand up. It's like they throw them under the bus instead of standing up for the trans kids.*
>
> *Parent*

One participant shared about the service 'They are a bit overly cautious and they don't really defend, I haven't seen them outwardly defending trans children from the media onslaught' (parent).

To see and hear more about the parent/carers' experiences, see the Healthtalk website resource (https://healthtalk.org/introduction/experiences-parents-and-carers-young-trans-and-gender-diverse-people/).

Chapter 7 Evaluation and dissemination event

In this chapter, we discuss the outcome of the formative evaluation of the Healthtalk resources and then discuss the dissemination event and its impact. In the next chapter we will present the main outputs from the research.

Formative evaluation

The purpose of the evaluation was to gain feedback from young people on the two new sections on Healthtalk.org and based on that feedback modify the sections as appropriate before going live. See *Chapter 2* for a description of how, where and when we ran the focus groups with young people and families (including parents and grandparents).

Feedback on design, navigation and accessibility of resources

See *Appendix 5* for feedback on the design, navigation, colours and accessibility of the resources.

Feedback on content of resources

Comprehensiveness and depth

There was strong approval for the comprehensiveness of the website. Some people were surprised at this: '[I] didn't expect so much content – I was impressed with the amount of content'. The depth and complexity of the resources were valued:

> *A lot of websites tend to stop at coming out and how you come out and often talk about one medical pathway ... but this went a lot deeper than that ... it went a lot deeper than anything that I have seen on other websites go.*
>
> *Young person*

Some wished they had this resource at an earlier stage in their life:

> *I spent an hour and a half on this ... if this had been something I'd come across [when younger] this would have been a month and a half of like reading a few pages and then like digesting it for a while and then re-reading it and going onto another section ... it's something that I would have like come back to for a long time and I think that's actually really vital. Like at that point I was so hungry for information, and having to go somewhere else because the first one [resource] you found was like keeping it brief ... having one trustworthy resource that has a lot is really great.*
>
> *Young person*

This was often talked about in relation to other information that was available on the web (see *Finding information*). Some valued being able to come to one resource, rather than multiple ones:

> *It is one of the most comprehensive single sources of truth that I've ever seen, and with my son going through GIDS, counselling, GPs and CAMHS as well – that has all been information from here, there and everywhere. And seeing it in all in one place is really, really good. It provided a lot of comfort. If I have got any questions then I would probably come here first before searching on any other site.*
>
> *Parent*

Others valued the flexibility of being able to return to the site: 'there's plenty there and you don't have to read it all at once and keep it in your head. You can dip in and out of it. Information when you need it' (young person).

A few people commented that the depth and complexity of the resources would 'future proof' it:

> *[Another web] site felt like it went out of date because it was a super safe, digestible and simplified narrative … and so when people are more hungry for a complex narrative so that stuff looks like it belongs in the past … this has complexity and it includes diversity and it trusts the reader to be able to take this at their own pace and digest new bits of information as they are ready for them so I think that is going to make that pretty resilient against feeling outdated.*
>
> *Young person*

Balance and optimism

People liked the realism of the sites, describing them as 'refreshing' and 'honest' with many feeling the resources were balanced. One person said that they appreciated that it wasn't 'all glossy and wonderful … you do need to include the stuff that's not that good. It would lose credibility otherwise' (grandparent).

> *It didn't skirt around the negativity and it didn't try and avoid talking about the less fun aspects, which is something you see a lot of, like a lot of coverage about the GIDS and getting healthcare … but it's very positively geared. Obviously there's that feeling of oh yeah that sucks and I hate this, but at the same time it was nice to see that it was talking about things that actually happened rather than the way it works or the way it doesn't. It was good to see a realistic perspective on it all*
>
> *Young person*

> *Found the profiles tab interesting – it brings it home that these are people, with real lives … and that you can actually have a fulfilling life as a trans person … all the media coverage that you ever hear is how hormones are going to ruin you and how it's terrible to be trans, you hear so much about the bad things that are happening to trans people in the UK at the moment. So it is nice to hear so many people talking about, you can have a life and it doesn't have to y'know end. Being trans can be a positive thing*
>
> *Young person*

A number of people felt the resources importantly captured both the positivity and difficulties of being trans or being a parent of a trans child:

> *It was interesting to see both sides of the story, some [people] had good experiences and got lots of support right from the beginning, and others that didn't get that much and trying to get information was difficult [for them].*
>
> *Parent*

People also talked about the hope and optimism they got from the resources. They felt this would help other young trans and non-binary young people. People were enthusiastic about the portrayal of trans people on the site:

> *It was optimistic and just refreshing to see people enjoying being trans.*
>
> *Parent*

> *It was nice to see older experiences and y'know that you can have a fulfilling life. It represents trans people as actual people which I feel is skirted over quite a lot. Trans people have normal lives, having all the different perspectives just showed them living their lives.*
>
> *Young person*

> *… there's so much media coverage and information about how hard it is and it's nice to have a resource which feels like, okay, 'what have we got?' and 'what can we do with that?' and 'how can you be helped by this?' – fundamentally as a trans and non-binary person growing up I would have really sought out a resource like this – a positive message that, hey look there is actually a lot of people in this space … it's about that positive reinforcement, it's about encouraging people to be open about that and have those conversations. And then, that is what makes change. Those people go out and make change.*
>
> *Young person*

Change was also talked about in relation to who might find the resources helpful. It was felt that the resources had a wide appeal to different audiences:

> *There's something here for everyone. Anyone can come on here and find a section on here that resonates with them. I think the balance is really, really beautiful. It's really hard to get a lot of information but this didn't feel overwhelming at all. The way that the videos are, the order of them – I didn't know if that was on purpose? It's a really beautiful journey and really informative.*
>
> *Parent*

People felt they would be important for health professionals to look at:

> *… it is possible to get good care and understanding from a GP and that is what we should demand and expect from more GPs and any GP who wants to improve the way that they treat trans people can use this as a resource for that.*
>
> *Parent*

Finding information

People spoke about the difficulty of getting information for themselves or family members and how much research they had done themselves (see also Chapters 4–6 where young people and parents discuss the difficulties of getting information). They felt that the resource was a helpful source of information:

> *Before this [resource], the only first-hand information that I got was from friends and people I met online, like someone I know online said that you have to become your own healthcare doctor, because well unless you know how to jump through loopholes, you've got to be your own source of knowledge and that's daunting … so going to all the healthcare sections [on the resource] were really good hearing people's experiences.*
>
> *Young person*

People said that there was information in so many different places, and that the information out there could be conflicting and confusing:

> *It can be easy when you are searching for things online, to find all these different articles and all these different sources and they'll tell you very conflicting things and it can be quite daunting and scary. I felt like with this website it felt like a source of truth for me. The amount of people you've talked to and the amount of information available. I feel like once it's launched I'm definitely going to be returning to it because I know I'll find it very useful.*
>
> *Young person*

People frequently reflected on how the information contained in the resources would have been useful for them at different times in their life:

> *Even when I transitioned 10 years ago, there was by that point lots of good information out there but you still had to dig for it. And you'll get this thing where you read something good in one place but then you'll then something else and you're like, I'm not quite sure that's right and you're having to work out which bits are actually authoritative, and which bits are kind of like they're taking a punt without checking*

> *everything … and finding your way through all that stuff can be very challenging, and daunting and I genuinely I felt like if I'd had a website like this [laughs] it would have taken a lot of the detective work out!*
>
> *Trans parent*

The topics and themes that people found most useful were those on everyday life and schools, diverse journeys/narratives, mental health and neurodiversity, sexual health, surgery, messages to others, media and working with professionals.

> *I like the fact that there's a big focus [on the website] on being trans isn't a single experience … there isn't this kind of one system or process that everyone goes through. It's very much like a personal thing – it's unique to you. The focus on that is quite comforting ... where you are and how it's going for you is completely normal and fine, and there's nothing wrong with going your own speed, doing it the way you want to… And you don't have to use anyone else's journey as a yardstick.*
>
> *Parent and daughter*

The topics on the media were highly valued in the young people resource. People felt that they could relate to what participants said on there and felt 'coping with the media' (topic) was supportive.

> *It's something very important and effects our lives a lot. It effects my life as a detransitioner a lot and it effects obviously trans people's lives a lot. I remember all the headlines, the impact it can have. So I think actually talking about that and talking about it from this perspective was something that was really good.*
>
> *Young person*

People also found the resources page on Healthtalk useful because 'it had a range of things like there was legal, there was support. It was nice to see a page dedicated to help'. The glossary page was viewed as 'good for educating people'. People also commented on those who were involved in the project ('Who made this resource' page) saying they valued knowing that the research had involved trans researchers and the website had been put together also by trans researchers. Another young person said, 'there was such a long list and obviously I know nothing about university research but seeing so many people involved in it was really nice to see'.

Diversity and range of experiences

People at the evaluation talked about appreciating the range of experiences reflected in the resources in terms of age, where somebody was in their transition, ethnicity, and gender. One person said, 'there were perspectives that I hadn't even considered before'. Another said:

> *… for me it was the first website that really focusses on non-binary people in terms of healthcare. I think there's an aside on the NHS website [where it] mentions non-binary people in passing, so it was really nice to see that.*
>
> *Young person*

People felt that other information or portrayals of trans people were too uniform, and too white:

> *With media and websites it's so common to see representation of white trans masc people. To have non-binary and people of colour is good to see. It was also good to see and made me smile to see the person who was 13 at the time of interview. That made me happy.*
>
> *Young person*

> *Normally when you watch trans things you only see trans men but it was nice to see a variety and especially a lot of non-binary/gender fluid people … you never really get that opinion of someone who doesn't fit the binary.*
>
> *Young person*

> *I feel like there's always improvements that can be made with diversity especially, like race and ethnicity … that's something always important to think about. But it wasn't like it was just all white trans men which I feel like is often the representation and it wasn't just binary trans people as well. Which is often the representation.*
>
> *Young person*

> *With my experience much of the stuff that I talked about in terms of gender was often dismissed as being part of my autism … the fact that this is a section in this and that it is discussed at length is really useful … I see and I'm present within this which is great.*
>
> *Young person*

One young person felt that it was helpful that the website discussed retransition/detransition in a supportive way:

> *Just the fact that you have spoke about [detransition] and have a very supportive perspective on retransition/detransition is more than a lot of places have done anyway. I was honestly quite surprised to see anything in it at all because it's usually just not discussed.*

Relatability and relevance: 'a microcosm of trans people in Britain'

People felt that they could relate to the stories and experiences they saw on the resources, even if those experiences were not the same or there were only parts of an experience they could relate to.

> *[T]here's a really nice, broad range of people from different ethnic groups, different gender identities and that feels representative of the country in which it is produced … This feels like a microcosm of trans people in Britain, which is great … where you are not going to relate to every part of everybody's story – you are going to relate to bits and pieces of other people's story. That's one of the best ways to organise something like this, have that range of voices so that someone can see themselves in any number of variants or perspectives.*
>
> *Young person*

People felt that the resources gave them realistic depictions of healthcare experiences:

> *[They] rang really true for me – a lot of it was exactly what I've dealt with. [Participants] talking about GPs and a lot of the time they can be less than understanding … the difficulties of getting an appointment at the GIDS, and about the UCAS form [participant mentions this on the site] my friends have just gone through this and how its just male and female on the UCAS [form]. A lot of it was very relevant and I could relate to it or I know people who could relate to it.*
>
> *Young person*

> *One common problem is that websites understate the problem saying that the waiting list is two years and you are reading it like, er no its way longer than that. This is very up to date and you even reflect the impact that COVID has had in exacerbating the situation … a lot of peoples' testimonies seemed to reflect that you have no clue when you will be seen … the fact that you are presenting all these diverse testimonies is way more helpful for giving a realistic picture than saying well this is what should happen … is better than having these like factual numbers.*
>
> *Parent*

> *I read the [summary] on the parent website about the experience of [GIDS] and it was exactly my experience like the four to six weeks appointments, the one person stays off (with one of the therapists) and then the parent goes off. That was exactly my experience. It was really hard to find any solid information about that at the time. So I think it's good that it was genuinely people's experiences and not just what they list off the website.*
>
> *Grandparent*

> *[The] Narratives topic summary hit home. I could completely relate because when I was coming out I was like oh am I trans enough?*
>
> *Young person*

People spoke about others who they thought the resource would be helpful for including family members:

> *Having the sections on parents, this website will be really useful to share with other family. Because we are our own little unit and we are accepting but you do come across other family members who perhaps, have more conservative views … I can even think of family members in my head – their understanding is that, there's just no moving. Not necessarily that there's a lack of acceptance but it's just that understanding and breaking through that barrier of getting them to see things in a different way and I feel that the content in this and how its presented would be really, really useful.*
>
> *Parent*

In particular, parents felt that the parent/carer resource was 'invaluable' in relation to misinformation and transphobia online:

> *It's so hard to get a good resource for parents. So much of what parents come across online is quite transphobic, written by people who don't have the best intentions.*
>
> *Parent*

> *When the parents are talking about the shock that they have experienced or some people are talking about how they sort of knew from a young age. I think having the diversity of the differences and how all these people are still valid in their identities was again something that is quite good. Rather than pushing the narrative of, the parent knows from when the child is two and is never surprised.*
>
> *Grandparent*

Content modification made to the sites

In addition to design/technical improvements, see *Appendix 7* for content changes made to the site as a result of the evaluation.

Collaborative dissemination (national networking) event

Following the evaluation, we held a dissemination event. In discussion with the funder, it was decided that showcasing and celebrating the three funded HSDR research projects together would generate better collaboration, opportunities and more effectively connect people together, rather than just running multiple project events. Due to the COVID-19 pandemic, the national networking event (planned to be held in person) was moved online, and was re-named the dissemination event.

The aim of the event was to disseminate the research carried out across the three NIHR-funded projects and provide an opportunity to gather key stakeholders, including academics, practitioners, policy-makers and third-sector representatives, to think together about how the findings can positively impact policy-making decisions that improve trans health care. The event was attended by over 60 key stakeholders including experts in transgender law, clinical psychologists, representatives from LGBT charities, academic researchers in trans health, and programme managers from gender identity services. A positive effect of holding the event online was the high attendance, which may have been more difficult to achieve in person.

The event was held in February 2022 at the time of the launch of the website resources. It was led by our co-applicant JS from Gendered Intelligence. Gendered Intelligence is a trans-led national charity whose aims are to increase understandings of gender diversity and to improve the lives of trans people. They deliver a range of services from work with young people and the community: working with professionals attending to their educational needs with regards to trans inclusion and engaging with the media, affecting public policy and partnering with other organisations and universities to carry out research about gender.

The event consisted of an introduction and welcome from JS, RM and other team members with three presentations of key findings from each project, before going into breakout rooms to allow more in-depth discussion of each project. MS and SM presented the Oxford findings first, followed by 'The Longitudinal Outcomes of Gender Identity in Children (the LOGIC Study)' delivered by Eilis Kennedy from the Tavistock and Portman NHS Trust, followed by 'Before, during and after gender identity specialist services: service models and experiences' from the Open University team led by Richard Holti, Ben Vincent and Sam Hope. There was encouragement to ask those attending the event to consider the perspectives they brought and ask: *What can and will come about because of this research? How can the research be put to use?*

Stakeholders were encouraged to abide by Gendered Intelligence's working agreement, creating a safe and supportive space to allow attendees to learn and think together. The six points of the working agreement were: respect; ensuring confidentiality; valuing diversity; supporting one another; engaging in critical thinking and reflective practice with care and carefulness; thinking creatively.

At the end of the session, everyone gathered back together to look at key learnings and takeaways. This generated a lot of very thoughtful, interesting conversations chaired by JS. There was positive feedback on the facilitation of the event, as well as the rich conversations led by the researchers. Stakeholder feedback strongly agreed that the research was relevant and important to them and that they were given the opportunity to participate in the event. There were reflections about how positive it was to have a space to network and build connections with others working in similar areas:

> *Really enjoyed the session today - it's always heartening to see this work getting done, and the networks that we build up.*
>
> *Building connections between research projects and the communities that their research affects.*

Key themes for developing the two films

In the breakout session led by MS and SM (Oxford team), participants were asked to consider: *what do you think are the key service improvements and recommendations to help health and care staff to respond effectively to young trans people and their families?* And *what themes would be important to show in a compilation film?* In Table 2, the main themes emerging from the breakout session were on: (1) mental health support; (2) experiences of GPs and primary care; and (3) diversity of experiences with corresponding discussion about what would be needed for service improvement. In the table, we paraphrase the words of participants in the breakout space.

Our introduction films on both resources were developed to ensure these themes were included in the films. We made sure that those young people or parents/carers talking about their experiences of GPs and doctors, as well as diversity and difference and mental health were in the compilations.

After the dissemination event, we asked for further feedback from participants, and again asked what their main priorities for service improvement were:

> *Unacceptable waiting times for young trans people to access consultations*

TABLE 2 Key themes from breakout session

Themes	Problem	Service improvement need
CAMHS/Mental health	CAMHS lack the expertise/clinical knowledge to support issues of gender dysphoria.	Resources for support. Appropriate use of pronouns, not misgendering clients. Validating people's experiences.
GPs and Primary Care	GPs being encouraged not to provide health care from practice managers. Poor communication regarding shared care (private care/GICs). Don't know of their obligations for shared care.	Educate practice managers on the obligations of shared care and how to work with private care/GICs.
	Many GPs are not confident enough to prescribe hormones. Even though they could, they won't.	More learning on informed consent model – a good way to deal with bridging prescriptions.
	GPs don't appreciate the urgency to provide care. Lack of confidence talking about gender/dysphoria. Lack of a personalised service. GP time is so short time slots and dedicated to one topic only. No 'checking in' part of the consultation.	Education at primary and secondary care level. Educate health care to the language of rights and to teach them that young people have the right to health, the right to participation the right to be informed. Gender champion – provide a personalised and personable service.
	Lottery of finding a good GP. You could get one good GP and then it could fail in another area.	Engaging with third sector/trans led charities to reach people who are not registered and provide them with healthcare advice.
Difference and Diversity	We cannot treat all young people as the same (using the same model).	Move away from one model of care. Empower professionals to be supporting young people in their locality.
	More work needs to be done to be inclusive and meet needs of range of ethnicities and cultural backgrounds.	Engagement with diversity within trans community. Move away from protectionist and pathologising interpretation of trans identities.

> *We need to promote the expert [trans] voices, and do so in a unified way. Why are courts and politicians treating people from unrelated fields as experts*
>
> *I do think we need to do far more about resilience development for the community, including good body care, wellbeing development, and personal knowledge as one of the biggest issues I find is how many of the community and the clinics are ill informed about rights and the law*
>
> *Just a wider acknowledgement of the diversity of needs, experiences and feelings of those in the community.*
>
> *I think the voice of the practitioners - dealing with levels of demand that outstrip their resources - also needs to be heard*

We then ensured that the themes of waiting times, listening to trans voices/experts, resilience and self-care were also featured in the introduction/compilation films. These are also in topic summaries featured on both resources.

Feedback was provided by participants on the resources when asked what people found most useful about the event:

> *Learning about the healthtalk.org resource, about young TNBI [trans, non-binary or intersex] people.*
> *I love the Healthtalk website; it's incredibly informative and is already on the list of excellent resources for our help line staff to share with service users.*

Other general comments include:

> *I found the whole day really exciting, extremely well organised, and loved the discussions – can't wait for the reports.*
> *I have welcomed today's session. Thank you Jay. It shows there is so much good work being done and that we can and should work together to make big and systemic changes. We need to make the truth work for the people whose lives are being negatively affected by the current broken system.*
>
> *Really good. So useful to see the outputs from the projects. I found it particularly important to think about how the datasets/analysis can inform policy/legal choices outside of the health sector as well. Thanks for the great discussions!*

In the next chapter, we continue to chart dissemination activities and their impact.

Chapter 8 Outputs and impact from the research

In addition to the dissemination event (see *Chapter 7*), we have shared information on and findings from the research throughout the project, as well as participated in policy and practice consultations, talks, presentations and produced academic outputs. Here, we provide an overall summary of the main outputs and impact from the research (14 in total) both in line with and in addition to the protocol.

a. The major output from our project is the production of two comprehensive Healthtalk sections for: (1) children and young people; and (2) families of transgender people. The target audience for both continues to be trans and gender-diverse young people and their families, the wider public, media, teachers, researchers and policy-makers (see below for the dissemination of this). The two new Healthtalk resources are both freely and publicly available. 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.
   https://healthtalk.org/introduction/experiences-trans-and-gender-diverse-young-people/;
   https://healthtalk.org/introduction/experiences-parents-and-carers-young-trans-and-gender-diverse-people/
   Reach > 500 (Healthtalk was accessed over 7 million times in 2020)
b. Two short summary films for service improvement are on the homepages of each section – in discussion with dissemination event participants, the main themes drawn from the breakout space helped to develop the compilations. The two films provide understanding of the core issues (such as GP interactions, diversity of experiences) facing young people and parents/carers with recommendations for service improvement. Reach > 500.
c. We have presented our findings at a number of events with further conference presentations planned:

   i. February 2022: MS and SM presented findings at NIHR collaborative dissemination event while JS, RM hosted/chaired the event. Reach > 50. Audience: academics, clinicians, managers and policy-makers.
   ii. April 2022. MS and SM presented at the Feminist Gender Equality Network ‘Living Gender in Diverse Times’. Reach 101–500. Audience: academics, international community; clinicians, students.
   iii. Forthcoming: MS and SM to present at Tavistock and Portman NHS Trust; Reach 101–500. Audience: clinicians, practitioners.

d. NIHR HSDR final report. Reach 101–500. Audience: academics, clinicians, managers and policy-makers.
e. Academic papers. In our protocol we said we would write two or three peer-reviewed papers. Two academic papers and one book chapter have been published from the research project thus far, with two further academic papers in preparation and a book totalling six academic outputs. Two papers are written in collaboration/inclusively with members of the advisory group. We have also discussed writing a further paper with our TPOC panel (pending).[36,72,102–105]
f. A change to one output of the project is dissemination with the Collaboration for Leadership in Applied Health Research (CLAHRC). Funding for the NIHR CLAHRC Oxford ended on 30 September 2019, replaced by the Applied Research Collaboration for Oxford and the Thames Valley.
g. Further, the risks of adding the two interview collections to the HERG archive were weighed up with the experiences of harassment and the sensitivity of the data. With participant safety paramount, this was unfortunately not possible.

h. In light of the above, the team produced further outputs to disseminate findings, including talks for public engagement and outreach, as well as non-academic articles:

    i. 2023: Martin (peer reviewed digital magazine for the British Pharmacological Society).[106]
    ii. May 2021: SM BBC Radio Oxford interview about research project and non-binary identities on their evening show. Estimated reach: > 500. Audience: media (as a channel to wider audiences), general public, professional practitioners, industry/business, patients, carers and/or patient groups, third-sector organisations.
    iii. 2021: Social Work England ('Social Work Week') SM participated in multidisciplinary panel on how social workers can improve their practice with LGBTQ+ people. Raising awareness of trans issues and discussion of research. Estimated reach: > 500. Audience: social workers, social work and postgraduate students, practitioners in social work field.
    iv. 2021: Rotherham Doncaster and South Humber NHS Foundation Trust (awareness training). SM, together with a member of the SSC, gave an online talk to mental health practitioners entitled 'Understanding the reality of trans health care: trans and gender-diverse young people'. Estimated reach: 101–500. Audience: NHS practitioners.
    v. 2020: SM participated in a podcast with a member of the SSC called 'Trans futures'. Discussed the research project. Estimated reach: > 500. Audience: international trans community, general public.
    vi. 2020: MM invited respondent at London School of Economics event on the role of the state in regulating gender. Estimated reach: 51–100. Audience: general public, undergraduate students, postgraduate students, practitioners, academics.
    vii. 2020: Oxford GPs, Oxfordshire. SM gave a talk entitled 'Reaching the bridge – health experiences of trans and gender-diverse patients' to GPs at a professional development day. This was a short training session highlighting key trans health needs incorporating early findings from the project. Estimated reach: 11–50. Audience: GPs, practitioners, allied health professionals.
    viii. 2020: University of Bath professional development day. SM presented 'Reaching the bridge – health experiences of trans and gender-diverse patients'. Estimated reach 11–50. Audience: postgraduate students, practitioners, academics.

i. MS has continued to support doctoral and masters' students in topics on trans health care, with the resource being used to aid discussion on research priorities.
j. Our advisory group and co-applicant networks have shared our resource to maximise the reach of it. Mermaids, the national charity established in 1995 to help gender-diverse young people and their families, incorporated the two resources into their training guides for staff. Helpline staff will also recommend young people/families to look at the resources. The GIRES has also featured the web resources on their website which details the research and links to the resources. Gendered Intelligence have featured the web resources in their 'Trans Inclusion Resource List for Professionals'. DIPEx shared the resources on their social media channels and networks. Estimated reach: > 500.
k. Since June 2022, the Kite Trust has been recommending the resources in their training of healthcare professionals. Feedback from this has been very positive 'We've been recommending your Healthtalk trans & gender questioning YP's webpages and project outcomes during all our training to healthcare professionals, it's a brilliant resource so thank you & congratulations!'. Estimated reach: > 101–500.
l. Further, in line with our protocol of maximising the reach of our research, we have contributed to/been consulted on policy and practice:

    i. Consulted for the Department of Health and Social Care Women's Health Strategy (2022).
    ii. Shared study details, methodology and findings and website with members of the Cass review team (2021–2).
    iii. Participated in the advisory committee of the Trans Learning Partnership (2020).

    iv. Constituency Office of Zarah Sultana (Member of Parliament for Coventry South) – distribution of resources to casework team for inclusion in any public engagement in support of trans constituents.

m. Our SSC members have been disseminating the resources and using them in training:

    i. They are now being used in LGBTQI+ awareness training at Oxford Health NHS Foundation Trust, through the SSC Patient Experience and Involvement Lead for Children and Adolescent Mental Health Services, who organises this training. SM was invited to be part of the formal working group and has participated in various sessions and feedback. The training is developed with young people who are experts by experience and patient participation groups.
    ii. The resources are being distributed and promoted by Jessica Lynn (Stonewall School Role Model, global ambassador and trans advocate/educator) at international events, invited talks at universities, schools and corporate events, who regularly talks to large audiences at these events. Estimated reach > 500.

n. MS and SM have been consulted on equality, diversity and inclusion, particularly on trans inclusivity at the following:

    i. NIHR Equality Diversity and Inclusion, SE Research Design Service (2022).
    ii. Contributed to the development of pilot workshops for Oxford University Medical School (2021).

o. As per our protocol, RM has a track record of engaging primary care audience on sexual and reproductive health issues and is facilitating dissemination of outputs to a primary care audience in a variety of ways, including:

    i. An article for the GP magazine Pulse on the reorganisation of gender services and what this means for primary care (in preparation/draft).
    ii. Engagement through social media such as X (formerly Twitter; two accounts –@GP_Sexual-Health and @Richard_GP – combined count of nearly 6000 followers).
    iii. Dissemination and engagement through GP Facebook groups.
    iv. As a member of All-Party Parliamentary Group on Sexual and Reproductive Health, he is able to discuss the findings with key policy-makers at future meetings.

Chapter 9 Discussion

In this chapter, we summarise the main findings of the research, in relation to our aim of producing a rounded understanding of the perspectives and experiences of young people, parents/carers, and health professionals (GPs, CAHMS, GIC clinicians).

Summary of data from trans and gender-diverse young people

> *As a trans person you constantly have to convince healthcare professionals that you are trans … and you are essentially trying to convince someone who has never had anything close to the experiences that you have of your experiences.*
>
> *Young person*

This research has sought to better understand how young people navigate and experience health services. Such evidence is vital to better meet the needs of trans and gender-diverse young people.

The interviews carried out with trans young people in this study show that the current healthcare system does not cater for the diversity of trans identities and needs. Currently, and often, a linear, one-dimensional understanding of trans identity exists. This traditional, binary and *white* conception of gender identity is restrictive and does not reflect modern gender identity experiences among young people, where there is a plurality and fluidity of experiences. Non-binary needs, for example, are often bypassed/not catered for in NHS services. Young TPOC face additional barriers and discrimination in healthcare services. It is these crucial nuances that contribute to significant health inequalities for trans young people, but also within trans young people populations.

Young people, particularly those who do not fit a linear or binary transition, often fear that they are ‘not trans enough’ when approaching healthcare professionals for help. There is little room for exploration (of identity) in health services (both at primary and secondary level), and young people fear that if they did not fit such a model, care would be denied. The threshold for trans patients was felt to be too high, with models of trans health care still being based on outdated, psychiatric/medicalised and pathologising ideas. Young people perceived NHS services as built around a culture of pathologisation, ‘gatekeeping’ (control of resources and treatment) and trans hostility fuelled by misinformation. Wait times of over 2 years meant that young trans people felt their needs were unimportant and overlooked by those who make decisions about health care. These feelings of discontent about services and healthcare professionals, resulted in a general level of mistrust in health services.

As a consequence, young trans people are anxious when approaching health professionals for help – sometimes this can be a GP who might be the first health professional a young person sees, or it might be when the young person is desperate 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.

The issue of trust sometimes led young people to resort to self-medicating (with the associated risks of this) and sometimes changing their identities or needs just to obtain medical care or be recognised in the system. The fragile relationship between doctor and patient meant that when communication and respect broke down, it could result in division, secrecy, and mistrust as well as risk taking, lack of self-esteem and ultimately poorer overall health for the young person.

Young people did talk about examples of good care they received, although these were not the norm. It was appreciated when a health practitioner was a visible advocate for trans health care, or that they had done research on a process or pathway, or had previous experience of treating trans patients successfully. Young people appreciated honesty when encountering a GP or other medical professional when they were new to trans health care – especially those who tried to help and were empathetic – as long as this was backed up by action (such as a prompt referral or agreement to find out about shared care).

However, while there were pockets of good care and examples, unfortunately, medical professionals generally 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, but they also felt that GPs 'could quite easily' do some research on trans issues, as they ultimately had professional authority (and therefore power) over the young person. What young people wanted to see, therefore, was less hierarchy in these encounters and more equitable, shared decision-making, based around an informed consent model (see also *Chapter 10* for recommendations). They wanted to work in partnership with healthcare professionals in equal relationships that recognised their autonomy and expertise over their own bodies.

All young people spoke about the wider trans-hostile environment in the UK and how the circulation of harmful and damaging media stories influenced the care that they received. Young people said mainstream media channels were 'right wing' and trans-exclusionary groups associated with 'TERF-ism' spread misinformation – these were seen as 'the voice of a few spreading negative messages'. It was frustrating when their lives (and medical care) were 'sensationalised' leading to dangerous fearmongering. Young people were angry that some journalists were unethical when reporting on puberty blockers – prejudiced stories were often at odds with participant's own experiences. The idea that treatment was being 'rushed' did not match their experiences. Fearmongering was seen as directly promoting 'horrific views on trans people' and influencing suicide rates among young people. Further, it was felt that while there was the rare occasion of positive media reporting, trans people were generally reported in medical terms only reducing them to their 'genitalia or hormones'. Young people felt completely disappointed and 'in a corner' with this. Negative coverage was seen as a way to spread fear and essentially avoid exposing the real issues that affected young people 'to prevent proper, informed, supportive trans health care'.

For those with disabilities, chronic illness and neurodiversity, needs were often completely overlooked and not met in healthcare settings. Young people spoke about wanting to tell a healthcare professional that they were autistic but hid this because of the ways in which autism and gender identity are wrongly conflated and fears about treatment being withheld.

Trans people of colour spoke of how a lack of cultural competency amongst health professionals meant that they experienced ignorance and (medical) racism. Trans young people of colour felt that they were generally not represented in any training, guidance or university (medical) courses. These young people become adept at 'hiding their pain' in healthcare interactions. Better experiences for a young person were when they could identify with and see themselves represented in the views and experiences of the health professional they were interacting with, for example, TPOC clinicians.

Young people used a number of strategies to survive and cope. Online communities and charities provided a lifeline for many. Sharing their different journeys, experiences and sharing details about procedures and treatments were critical in providing support. Some called this 'mutual aid' where there were reciprocal relationships of help between friends and communities. Counselling and communal support were also important for young people to improve their well-being. This often involved coming to accept themselves and take pride in their identities.

Summary of health professional data

> *[D]octors are scared. They are scared of doing the wrong thing. What actually I feel they should be scared of, they should be more scared of is doing the wrong thing, which is not supporting trans young people. And by not supporting trans young people, it's not a neutral option …*
>
> *GP*

> *I absolutely don't feel safe. I don't know what I am doing. I don't feel I have adequate training or support.*
>
> *GP*

This research has sought to better understand health professional experiences (including those from 'gateway' services such as GP surgeries, CAMHS, GIDS, and GICs). Such evidence is important to better meet health professionals' needs. A summary of the main findings is available in the peer-reviewed *British Journal of General Practice.*[36]

In brief, four key domains were identified that prevent trans and gender-diverse young people receiving good-quality care; these were structural, educational, cultural and social, and technical barriers. In *Chapter 6*, we expand on these to discuss themes of negotiating risk, and working with families.

Many health professionals interviewed had significant awareness of the structural issues they and others faced. They spoke about the shortage of services, long waiting times, lack of guidelines and lack of funding and support. Health professionals also reflected on the current models and pathways of health care, and some felt these could be too rigid and that it did not take into consideration individual needs.

Reflecting on the approaches professionals took with young people, the issues of trust and autonomy emerged. Some of those interviewed felt that young people were not taken seriously, despite young people showing capacity for making decisions. Others spoke of a lack of informed consent in decisions about treatment. The approach of exploration in gender specialist services was viewed by some as a move away from understanding and respecting the autonomy of young trans patients. Several professionals were also very aware that young people were reluctant to explore their gender identity when coming to specialist services, because they knew it would impact on their treatment further, when they had been waiting for years.

At the same time, some professionals felt that exploration of other issues was important, and that this was a valuable model adopted at gender specialist services. This included general feelings about identity, body image and self-esteem. Some felt that young people on the waiting list might be better served with general mental health support rather than specialist gender help. Such ideas link to young people's experiences where health professionals have incorrectly insisted on a referral to mental health services rather than gender specialist services.

While there were differing opinions on approaches in health care, all professionals, particularly GPs and nurses, thought that trans health was not sufficiently covered by their education and training. This theme emerged repeatedly in all data sets (see summaries of parent/carer data and trans young people data below).

One of the consequences of a lack of education and training for health professionals, particularly GPs, meant that some felt they were 'taking a risk' at times. Some GPs said they didn't 'feel comfortable', they were 'unsure', they lacked 'confidence' and didn't have 'sufficient knowledge'. Some said they were not backed up by their practice or practice manager, even when they wanted to prescribe or make decisions about shared care. Other health professionals felt that 'doing nothing' despite this, was not a 'neutral option' given the negative consequences for young people.

In terms of attitudes to trans people, health professionals spoke about negative attitudes and prejudice towards trans people in their 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. This significantly affected the care provided to trans and gender-diverse people.

Finally, technical and administrative issues created further barriers to providing good-quality care. Inflexible computer systems, display systems, as well as waiting rooms meant exclusions on a number of levels from necessary check-ups and scans to unnecessary misgendering.

Summary of parent/carer data

> *I realised how important it would be for me to be as supportive [of my trans stepdaughter] and understanding as possible in a world where she may not always experience support and the opportunity to express herself and not feel that she should pretend to be someone she's not.*
>
> *Parent*

This research has sought to better understand how parents/carers navigate and experience health services. Such evidence is vital to better meet parent/carer needs.

The interviews conducted with parents and carers of young trans and gender-diverse young people in this study demonstrate that the healthcare experiences of parents and carers supporting their young trans and gender-diverse people are marked by a multitude of challenges. These challenges occur at all stages of the pathway and range from getting their young person referred to specialist gender identity services, lack of support during waiting times through to sometimes unclear and lengthy assessment processes, which many experience as 'gate keeping' of gender-affirming care at specialist services. While not all participants reported experiencing all these issues, many shared having encountered several of them. These challenges have a negative impact on the young person and their close persons/loved ones. Worryingly, participants frame positive experiences within health care – both primary and specialist – as 'lucky' as opposed to the expected standard. Relatedly, the care received from gender services varied, depending on the clinician encountered. Some parents compared this unfavourably to other country's clinical care. These findings highlight the urgent need for improvement across all healthcare settings.

The following main barriers to providing good-quality health care to trans and gender-diverse young people were identified:

- Lack of understanding and knowledge of trans identities and health in primary healthcare professionals and CAMHS, which leads to delay of referrals and at times treatment.
- Trans-negative attitudes and prejudice towards trans and gender-diverse people among healthcare professionals and at times denial of care.
- Scarcity of specialist services and the resultant exceedingly long waiting times, which leave families waiting and unsupported for years.
- Gate keeping of gender-affirming interventions and lack of clarity about the assessment process within the GIDS and cisnormativity of the service.

Parents and carers of young trans and gender-diverse people have unmet support and information needs. For families on the waiting list, support is practically non-existent within the NHS and there is little signposting to existing support groups and charities. When it comes to information, parents and carers report feeling that their often-extensive knowledge and expertise – which they gather independently in their effort to support their young person – is not valued within healthcare settings. This is disempowering in particular in the context where healthcare professionals lack knowledge on trans and gender-diverse health and identities. Moreover, the gathering of knowledge by parents is also dependent on their social and cultural capital that is their education, financial means, and so on. A lack of reliable sources of information can also mean that parents and carers need to filter through a lot of information that is incorrect and at times harmful.

The main findings for this part of the project were that parents and carers feel largely unsupported within the NHS and that more support is needed for families of trans and gender-diverse young people. Within the NHS, the scarcity of provision, as exemplified by the long waiting times for specialist services, combined with lack of education and awareness about trans and gender-diverse children and their needs in primary care settings and CAMHS, present serious challenges for parents and carers. Lack of knowledge and experience of healthcare professionals' means that parents largely shoulder the burden to gather and filter information about gender-affirming care and at times are burdened with educating the healthcare professionals, on whose care their child depends. To help them navigate the healthcare pathway and to meet the needs of their trans or gender-diverse child and their families they rely on peer support groups (online/face to face) and charities. These sources of support are, however, not well signposted within the NHS. There is an urgent need for better support for families waiting for specialist services.

The NHS services also have a role to play in providing up-to-date and accurate information on gender-affirming care. Within the remit of that role, the NHS should be more proactive by helping to debunk harmful myths about gender diversity and trans children, to positively affect the public debate and contribute to depathologising of gender diversity and trans identities and lives. For that to happen, gender services need to ensure pathologising views are not reproduced and sustained within their own ranks. Trans and gender-diverse young people have a right to timely and affirming care. Without introducing changes and actively working to reduce barriers that trans and gender-diverse young people and their families face in health care, the NHS will continue to fail these underserved groups.

Chapter 10 Conclusions and implications

This research has sought to improve the care and support of gender-diverse young people and their families, through identifying possible improvements to care and by providing resources, information and support for self-care and management.

Below, we summarise the main recommendations for improvements arising from this research, before detailing the resources developed to support young people and their families before and after referral to specialist gender identity services. We then discuss the core strengths of this research, as well as limitations and possible future directions of research.

Main recommendations/improvements

From our exploratory research data, we suggest the five main recommendations for improving care are:

1. Empowered decision-making for trans young people.
2. Recognise and cater for diverse needs.
3. Baseline, mandatory training for health professionals that is trans positive.
4. A restructured depathologised service in partnership with trans-positive gender specialists.
5. The NHS positively affecting the public debate and challenging misinformation.

1. **Empowered decision-making for trans young people**

Our research data suggests, new models of health care should:

- Respect the autonomy of young patients to make responsible and informed decisions about their health care.
- Endeavour to regain and build trust between trans communities and healthcare professionals. Young people had little trust in healthcare professionals, so this urgently needs building.
- Empower young people to embrace their identities, irrespective of medical intervention.
- Ensure young people feel that they are listened to, believed and not viewed as a 'confused child with gender distress'.
- Healthcare professionals working in partnership with young people. Young people believed that good health care comes from feeling empowered to make the right decision based on the best knowledge and research available that recognised their autonomy and expertise over their own bodies.
- Parents/carers felt largely unsupported within the NHS and rely on charities and support groups for help. New models of health care need to consult and be led by affirmative charities and community groups (those that actively support trans young people).
- Help young people take pride in their bodies at each stage of transition.
- Respect the expertise of lived experience. View young trans patients as experts in how they feel.
- Re-envision gender identity services as open and welcoming spaces for trans young people with integrated support from other services, including charity sector organisations that are trans led with input from local youth groups.

2. **Recognise and cater for diverse needs**

Open and equitable health care should:

- Understand the diversity of trans bodies and pathways, not just one linear, binary pathway. Young people felt the current healthcare system had a linear one-dimensional understanding of what it is to be trans. Encourage inclusive understandings of trans identities.

- Move away from stereotypical gendered expectations, particularly white, able-bodied, binary expectations.
- Dismantle the threshold and diagnosis of 'gender dysphoria'.
- Strive for better communication in healthcare environments, including the use of language that includes *all* identities.
- Young people feared they were not 'trans enough' when going to doctors. Have an appreciation of all gender presentations as valid and 'trans enough'.
- Understand, listen and meet the needs of non-binary young people in gender identity services.
- Validate multiple trans pathways through healthcare services, ensuring multidisciplinary teams provide services where young people can move between different elements of a service without the need for re-referral.
- Targeted recruitment of trans and TPOC clinicians in healthcare services so that diverse groups of trans and gender-diverse people feel represented within the service and improve relationships between trans people and clinicians (see also below).

3. **Baseline, mandatory knowledge and training for health professionals that is trans positive**

Our research data suggest new models of health care should:

- Ensure clear, comprehensive and mandatory training pathways for all healthcare professionals. All health professionals interviewed wanted this. Health professionals should have a comprehensive knowledge of trans health care, pathways, and processes should be trans positive and enabling. Such training can include a 'radical empathy' approach[25] – particularly for those clinicians with little or no experience of trans patients. Fundamentally, this relies on a foundation of acceptance of trans and gender-diverse identities as real and worthy of care.
- Ensure avenues for continued professional development in trans health care.
- Detailed knowledge of trans healthcare processes and procedures, for example, in primary care, deeper understanding of referral processes, and follow-up shared care agreements.
- Have training that focuses on the needs of marginalised groups within the trans community, including TPOC, neurodivergent and economically disadvantaged trans young people. Services should consider the needs of homeless trans young people and how to reach those in care/care leavers.
- Improve representation of people of colour in gender identity services. Recruitment within gender services should prioritise LGBT+ people of colour. Evaluate why recruitment of clinicians of colour is difficult – anti-racist and anti-oppressive policies should be supported by effective discrimination policies and strong management.
- Focus on the upskilling of trans and gender-diverse people to bring valuable first-hand experience into health care and improve visibility within trans healthcare services. Trans people have valuable first-hand knowledge that is important to patients which helps establish empathy and rapport with clients.

4. **A restructured depathologised service in partnership with trans-positive gender specialists**

From our research data, restructured healthcare services should:

- Depathologise gender identity in healthcare services. The proposed future alignment with paediatrics 'with a focus on child health and development, with strong links to mental health services' should not be licence to further gatekeep or pathologise gender-diverse young people.[107] Paediatrics does not have a history of gender specialisms, therefore considerable training and development and financial investment would be needed in the long term.
- Adopt robust feedback systems to monitor the care that young trans people receive (e.g. patient-reported outcome measures for young people – see Kamran *et al.* 2023).[108]
- Move away from a psychiatric model of diagnosis and towards an informed consent model nationwide. This should align with wider and long-overdue reforms to the Gender Recognition Act.

- Remove barriers to accessing mental health support. Mental health support referrals should be available quickly for the support of young people without the need for re-referral. Long-term investment in trans positive mental health provision. Concurrent referrals are needed with joined up service delivery models of gender-specific services and mental health provision that work together.
- Localised gender hubs at primary care level. Roll out more services similar to successful pilot schemes. Stronger linkages and co-production with national and local affirmative charities.
- Reconceptualise gender identity services as trans acceptance pathways.
- Ensure that administrative systems are able to accommodate new names and pronouns as well accurate and up-to-date gender markers.
- Adopt an informed consent model that enables trans and gender-diverse people to access appropriate treatment.

5. **The National Health Service positively affecting the public debate**

- NHS services have a vital role to play in providing up-to-date and accurate information on gender-affirming care. Within that role, the NHS should also actively debunk harmful myths about gender diversity and trans children, by proactively influencing public debate and contribute to depathologising of gender diversity and trans identities and lives.
- Provide adequate signposting for parents to access reliable sources of information.
- Gather, filter and provide information about gender-affirming care for health professionals and parents/carers. This could be achieved through the NHS providing 'official' information sources that are co-produced with the trans community.
- Reconfigured gender services need to ensure pathologising views are not reproduced and sustained within their own ranks.
- Have robust guidance for supporting trans colleagues and trans allies in the NHS to counter discrimination.
- Critically evaluate limitations in the evidence base being used to advocate for withdrawal of treatment for young people.
- Finally, this and the other recommendations are ground in the need for a collective culture of responsibility in health care that requires change led by senior management in the NHS. Such a 'systems change' intervention approach will need to go beyond training for individual practitioners.

At the time of writing recommendations, the wider context of improvements to gender services are a continual shifting entity. Gender identity specialist services for children and adolescents are undergoing changes, where GIDS will be replaced by regional centres, which NHS England say will provide a more 'holistic and localised approach'. What follows will be recommendations from the national Cass review.

It is unclear how quickly waiting times will be affected, as well as the shorter- and longer-term experiences of both young people and their families. While GIDS did offer care in one main centre that already has regional outposts, there will be high expectations for a more integrated and thorough geographical offering to ensure equity of access at all stages. It remains to be seen whether this can be offered in a significant and sustained way. It is unclear what funding and training is committed and how this will permeate to work on the ground.

Previous service evaluations of nationally mandated transformations of child and adolescent services (particularly in a sensitive area) suggest this will be a huge undertaking and require well-thought-out planning and training of relevant staff.[109] Implementation of reorganisation can be significantly affected by poor communication and poor management, resulting in experiences of unpreparedness and destabilisation of services with staff dissatisfaction.[110] It is clear from social and online media that such proposed improvements to gender services for young people have had mixed reception, although there is both hope, high expectations as well as fears. The trans community need to be involved with decisions going forward and are best placed to evaluate the effectiveness of the proposed service changes.

Providing resources, information and support

This research has produced two vital online resources which provide information and support. The information on the Healthtalk resources will be important not only for young people who are gender diverse and families of gender-diverse young people, but also for health professionals who, we know, often lack training in, and understanding of trans identities, and healthcare options. Our research identifies a number of barriers to providing good-quality trans health care.[36] Medical professionals in particular cite a lack of LGBT+ training at medical school and report a lack of confidence in clarifying unfamiliar sexual and gender terms and finding support resources to help them.[111] The resources will also appeal to the wider public with our evaluation showing that there is 'something for everyone' – whether somebody has little or no knowledge or some knowledge of trans issues.

Five per cent of Healthtalk visitors use the website for work purposes – it is used across the globe in teaching, training of health professionals and those in other professions such as the police and social care.[64] It is also used in teaching in several medical schools in the UK, as well as informing clinical guidelines and service redesign.[64] In *Chapter 8*, we discussed how we were engaging a wide range of audiences to disseminate the resources.

The impact and strengths of this project were described by evaluation participants who spoke about the comprehensiveness, depth, balance and optimism of the resources. The evaluation showed that the diversity of experiences represented in the resources are a further key strength. These resources, as with all Healthtalk projects, provide relatability and relevance to those who view them, ensuring that people feel less alone, more confident and reassured.

Strengths and limitations of this research

There are many strengths of this research, as well as some limitations.

While there is currently a period of uncertainty with the restructuring of gender identity services, this research and the supportive resources, have applicability and longevity. We have taken a holistic approach to understanding trans issues, and many of the core research themes cover broad areas related to young peoples' health and parental concerns. Our evaluation found that the depth and complexity of the resources will ensure that they remain relevant.

Above all specific recommendations around depathologisation, working in partnership with trans young people and better trans-positive training for healthcare staff are even more important in lieu of the proposed changes. These elements need to be central considerations in how day-to-day operations work in any new service.

This research is based on the experiences of 91 trans young people, parents and health professionals. However, our remit was not a service evaluation as such and therefore did not measure or ascertain current practice in GIDS or GICs. What we have presented here are the experiences of trans young people and parents/carers of healthcare services to provide recommendations based on those insights.

A limitation is that the spatialised politics and nature of identity as fluid and evolving, means that our research is inevitably incomplete.[112] While a breadth of diversity and experiences have been represented in the resources (and as diverse a sample as possible recruited within relatively short timescales), there are likely to be some missing experiences going forward. Some of those were identified in the evaluation and are suggested below in future research avenues. Nevertheless, qualitative research, like this, does not seek generalisability to wider populations typically associated with quantitative research, but it can provide analytical generalisation, transferability and applicability to other (social or health) settings.[113]

Therefore the experiences in this research can provide a vital insight for NHS England in planning future service changes.

As discussed in *Chapters 1* and *3*, a core strength of our research is in being able to provide support through the development of the Healthtalk resources for young people on a waiting list for specialist services. The resources are incredibly comprehensive, at around 30,000 words, and have a broad diversity appeal for visitors as they include a wide variety of gender experiences. For example, there is significant non-binary representation within the resource. This is important when little research has previously focused on non-binary individuals even though non-binary people make up a significant portion of the transgender community.[114]

Further, while our remit was primarily for those on the waiting list, this resource is also relevant for people who are not on a waiting list and those who do not seek gender specialist services. It will be of interest to those younger adults in adult services, given the age range of participants in the young people sample.

A key strength of this project has been the strong relationships built over the lifecycle of the project with our collaborators. This was importantly from the outset, before any funding was granted. Our collaborators are experts in this area working with trans young people on a daily basis. While our community engagement remained strong throughout, it is acknowledged that a 30-month project is a considerable time investment and people's lives and priorities change. We also acknowledge that for research teams to successfully engage with community partners, sufficient time and resource are needed to do this effectively and in a genuine way. As with this project, this is often done as 'extra' work in a research project, but needs to be built into the application and prior to the funding cycle.

The development of TPOC panels during the research has meant that the representation of ethnic minority trans young people is at approximately 38% in the resource. This diversity in the young people sample is a core strength of the research as noted in our evaluation, but these relationships take time to develop. Ensuring that 'easy to ignore' groups are included takes thought and commitment.[115] It also involves a normalisation process which needs to be standard practice within research, with a concurrent recognition of the barriers that prevent this from happening.

Future research

Future trans research building on the work presented here and others leading in this field, could focus on homeless trans young people, sibling and grandparent experiences – particularly gender-diverse (grand)parents and those trans young people who are in care or care leavers. Given the NIHR remit on social care research, there is a relevant need for more research on trans equity and awareness in social services and social work, including multiagency perspectives as highlighted in the 2018 Department for Education research report on child and family social work education.[116] Further social care projects may also examine the experiences (and barriers) for trans social workers; trans carers and occupational therapists, as well as other practitioners. In our evaluation, participants highlighted the need for further research on trans parenting and the intersections of gender with other identity categories that shape the experiences of trans and non-binary parents, though we note there is growing corpus of work in this area for example on trans masculine and non-binary pregnancy, views of children with a trans parent and intersectional explorations of trans and non-binary parenting.[117–121]

Furthermore, one evaluation participant had recently detransitioned and felt that there was a lack of sensitive, supportive trans-positive information available. She also spoke about the dangers of detransition stories being 'weaponised' to withhold and lobby against trans young people's health care and rights. We concur with this participant that the development of sensitive information on this topic is needed. Further research is necessary to fully engage with the numerous complexities of detransition.

To prevent the area being weaponised as this young person described, it would require highly sensitive research that takes trans equity and adolescent rights seriously.

It is important to note here that research teams who work positively and sensitively with the trans community need much better support. As discussed in *Chapter 1*, there were numerous attempts to derail this research, which created additional pressures and stress. To ensure that trans researchers and cis researcher allies continue to do vital research in this area, urgent support is needed. A robust and genuine commitment to counter discrimination on university campuses is required to protect staff from relentless smear campaigns.

Further research is needed to evaluate the proposed changes to gender services to ensure they genuinely improve care for trans young people, who will be the main group affected by future changes to child and adolescent services. Current proposals suggest that an integral research network and research capacity will be built through the regional networks.[107] However, it is not clear who the stakeholders will be in this. A thorough ongoing service evaluation co-produced with trans organisations should assess the reforms. If ambitions to genuinely improve services for young people are realised, it is vital that any future research in this area (such as a service evaluation) should have trans young people play an active and central role. Tokenistic, repeated consultations will not suffice, nor will including and legitimising those with harmful views or agendas as this creates more burden, suspicion and scepticism among the trans community. Research that is supportive and enabling for the trans community is vital. Harmful research is that which pathologises trans people, is sceptical of the existence of gender diversity and/or creates further licence for barriers to affirmative care or treatment. Research that is trans led and/or has trans researchers in central roles on research teams should be prioritised to ensure that health experiences do finally improve in a sustained and long-term way.

Equality, diversity and inclusion

Finally, in line with NIHR mandatory reporting, the heart of this project has been a commitment to equality, diversity and inclusion principles and actions. From responding to the commissioned call, which highlighted the urgent need for primary research with gender-diverse young people to the diversity of our participants including TPOC panels, through to our strong engagement with community and charity partners and production of accessible resources on healthtalk.org, this research clearly underscores the urgent need for further research with marginalised young people who are gender diverse (see *Future research*).

Additional information

Contributions of authors

Melissa Stepney (https://orcid.org/0000-0001-8743-9443) Principal investigator. Conceived the study idea, proposal and design, established the PPI networks, conducted the literature review, led the project and the development of the Healthtalk resources including drafting and buddying the summaries and content, chaired the advisory group and team meetings, disseminated the resources, supported JS with the dissemination event, led the evaluation with SM, wrote drafts of the final report and gave final approval of the manuscript.

Samantha Martin (https://orcid.org/0000-0003-1473-493X) Researcher. Conducted the literature review, conducted and analysed the interviews with young trans and gender-diverse people and wrote topic summaries for the corresponding Healthtalk resource, developed the TPOC panels, disseminated the resources, supported JS with the dissemination event, led the evaluation with MS and contributed to writing the young people chapters, the health professional section, the evaluation, the dissemination, outputs and the recommendations of the final report.

Magdalena Mikulak (https://orcid.org/0000-0002-1519-7673) Researcher. Conducted the literature review, conducted and analysed the interviews with parents and carers of trans young people and developed the corresponding Healthtalk resource, and contributed to writing the parent/carer section of the final report.

Sara Ryan (https://orcid.org/0000-0002-7406-1610) Research lead and deputy principal investigator. Contributed to the study design, provided mentorship for the team and principal investigator, contributed to the development of the Healthtalk resources, and reviewed/edited the final report.

Jay Stewart (https://orcid.org/0000-0002-7759-3305) Co-investigator. Contributed to the study design, team recruitment, helped participant recruitment strategies and the formation of the young people advisory panels, contributed expertise throughout the study, supported the team and principal investigator, led and hosted the dissemination event, and reviewed/edited the final report.

Richard Ma (https://orcid.org/0000-0001-6877-2785) Co-investigator. Contributed to the study design, contributed expertise throughout the study – particularly to the interviews with health professionals and the clinical accuracy of the Healthtalk resources, supported the team and principal investigator, supported JS with the dissemination event and reviewed/edited the final report.

Adam Barnett (https://orcid.org/0000-0002-7603-8692) Co-investigator. Reviewed and published the final resources on the website Healthtalk.org and reviewed the final report.

Acknowledgements

The authors would like to thank the following:

First and foremost, our research participants (the young people, parents and carers and health professionals) who gave their time to speak to us about their experiences and reflections and shared their stories. We are incredibly grateful for your time, commitment and enthusiasm for this project. Thanks also go to the young people and families who helped us to evaluate the resources, and our attendees at the dissemination event, who provided feedback and input. Thank you to the skilled and talented actors who helped create the resources.

A huge thanks to our members of the advisory group, who supported the project throughout. Thank you for giving solid, unwavering support. You helped us with recruitment, reviewing topic summaries and providing critical insights at all stages. We are especially grateful to you for providing sage advice during repeated attempts to disrupt the research.

Special thanks go to our members of the youth panel, whose views shaped all aspects of the project. In particular, our TPOC panel gave us sharper and more critical insights into medical racism.

Thank you to the external members of the SSC chaired by Professor Steve Pile, who gave practical and sound advice to the team and principal investigator during difficult and challenging times. We are grateful for your advice at all stages.

Experienced qualitative researchers acted as research 'buddies' and supervisors for the resources, drawn from/affiliated to the Department of Primary Care Health Sciences at the University of Oxford. They reviewed the analysis performed by the researchers and contributed to the writing of the lay summaries of both Healthtalk resources. Thank you also to former team members who were unable to see the project come to fruition. Thank you to Phil Nieri for showing an interest in this project.

We appreciate the camaraderie and collegiality of colleagues working on other studies funded under the same HS&DR call with whom we collaborated to host the dissemination event. Gendered Intelligence hosted the event, and Hag provided fantastic expertise and management.

Jo Kidd of the DIPEx charity who (with Adam Barnett) published the final resources on the website Healthtalk.org. Thank you for providing support for the project; and for the additional time it took to make changes to the final resource.

Thanks goes to the NIHR who funded this project, in particular programme colleagues for your efficiency, responsiveness and sound advice.

Finally, we would like to thank our closest family and friends, who have supported us during this project – this support has been invaluable for each of us in different ways. As people, not just researchers, we have relied on your support to get us through some difficult and very challenging times. We hope you will share our joy in the final resource!

Data-sharing statement

The data generated by this qualitative study are not suitable for sharing beyond that contained within the report.

Ethics statement

The study is linked to the Healthtalk programme of studies and has ethical approval (Berkshire research ethics committee reference 12/SC/0495, 2017), which covers an ongoing series of studies that use the same qualitative research methods to collect narratives of health issues and use the website healthtalk.org as a primary dissemination route.

Information governance statement

The University of Oxford is committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. Under the

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Disclosure of interests

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at https://doi.org/10.3310/XCYT6530.

Primary conflicts of interest: Melissa Stepney is a consultant methodologist for the National Institute for Health and Care Research (NIHR) Research Design Service. Sara Ryan is funded by the NIHR Research Support Service, membership of the NIHR Research for Social Care (RfSC) Funding Committee, is a trustee of LMCP Care Link, was principal investigator on NIHR128616, and is co-principal investigator on NIHR135080 and NIHR131322. Jay Stewart, Gendered Intelligence, runs a range of professional training courses. Richard Ma was funded by NIHR Doctoral Research Fellowship (NIHR-DRF-2017-10-181).

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Appendix 1 Health professional interviews: topic guide

Role

- What is your main role/tasks that you do?
- What are your responsibilities in terms of trans health care? Where do you see yourself in the trans healthcare pathway?
- Could you describe the challenges specific to your role?

Training and education

- Can you start by telling me how you learned about trans and gender-diverse identities and trans health?
- What elements of trans health were covered (if any) by your education and professional training?
- What sort of training have you had, if any, to work with trans and gender-diverse young people?
- What would you say are the key support needs for health care professionals when working with trans young people?

Experiences: first meeting

- What are your experiences of working with young trans and gender-diverse people?
- What happens at a first meeting? With whom are they likely to arrive? How is it to have the parents/ others there? What do you think is important in that first meeting?
- In your experience, are there any differences between what a trans young person might want when they arrive and what you can provide?

Experiences: patient journey

- Could you talk me through the young trans patient journey through health care?
- How are patients supported in their decision-making along this journey?
- In your experience, are differences of race, class, ability, sexuality, location relevant to how that journey looks?
- What are your views on the waiting lists?
- What do you think could/should be done in the meantime?

General practitioners and primary care/working with others

- What is your experience of working with GP’s with regards to trans health care?
- How would you describe the initial role of GPs in providing care to trans and gender-diverse people?
- What do you think is important for GPs to be aware of when it comes to trans health care?
- What are your views on the support young people receive before entering specialist care?

Gender identity development service, National Health Service and other care

- Do you have any experience of working at GIDS?
- Is there anything you think should be changed in GIDS and NHS more widely in regards to trans health?
- What is your experience of trans young people seeking private health care?

Working with patients: other factors

- How do you manage patients who present with mental health issues (i.e. anxiety, depression)? How about risks of self-harm and suicide ideation?
- Do you have any experience of young autistic trans patients?

Language

- What do you understand by the term gender dysphoria? What about gender incongruence?
- How do you navigate language around trans and gender-diverse identities? How did you first learn about different terms and identities related to being trans?
- What is your experience with pronouns and preferred names?
- Can you think of any examples of good or poor practice?

Discrimination

- Do you think trans people face any biases in health care?
- What do you think could be done in health care to combat stigma and discrimination of trans people? How?
- Can you describe an experience that surprised you or forced you to change what you thought about trans issues?

Perceptions and power dynamics

- How would you describe the patient/professional relationship in your own work?
- What do you think about the levels of choice/autonomy that young trans people have in health care?

Working with parents/carers

- Can you tell me a bit about your experience of working with parents/carers of trans young people? Can you give an example that comes to mind?
- Are there any particular challenges that you come up against when working with parents or carers? What are the most common concerns/questions parents/carers ask?

Barriers/problems

- What factors complicate working with trans young people?
- What do you think is most important to trans patients when accessing health care?
- Could you describe a particular challenging experience you had in your role with trans young people? Can you describe a time when you were not able to meet the needs of a trans young person and why?

Resources and sources of information

- What resources do you use for supporting your work with trans young people? Are there any other resources you are aware of?
- Where do you think young trans and gender-diverse young people get information about their gender identity? Gender-affirming care? Their health in general?
- What do you think about the information available to young people? What is the role of the internet?

Future

- How do you feel trans health care could be improved? What resources would you like to see developed in the future?
- How can access be improved for young trans and gender-diverse people?
- What advice would you give to doctors and nurses working with trans young people?

And finally, a couple of questions about public debate

- What are your thoughts on the current interest in trans-issues in the public debate?
- Are you familiar with current debates about trans children?
- What do you see as the role of medical professions in these debates?
- Is there anything we haven't talked about you wanted to add?

Appendix 2 Young people and children interviews: topic guide

Personal journey

- Perhaps we could begin with you telling me a little bit about yourself? How did you come to identify as trans?
- How do you experience gender dysphoria/gender incongruence? Being trans?
- How have your family and friends responded?
- Can you remember where you first learned about gender/trans identities?
- What's your experience of getting information related to trans health care?
- How did you decide that you wanted to make steps towards your transition/seek out health care? Who did you share your thoughts/concerns with? family, friends or others?
- How did you decide? What was the first step in your journey?

Social transition

- Can you describe your social transition? Process?
- How do you feel about the changes you have made so far? What was it like at school/college/work?

General practitioner/referral

- What is your experience of visiting the GP?
- What has been your experience of getting a referral?
- Was there anything particularly helpful or unhelpful around getting the referral? Any obstacles/ issues?
- How would you describe the knowledge of your GP about trans issues/gender identity?
- What do you wish GPs understood more or knew more about?

Waiting list/between appointments

- What is your experience of the waiting list?
- What support do you have in between appointments?
- Gender identity development service
- What is your experience of GIDS? How did you find out about it?
- Can you describe what happens? How was it getting to the appointment?
- What do you want from GIDS at this time? Why?
- What is your experience of the assessment?
- What happened? Who did you speak to? How did you feel? Who came with you? How was that for you?

Hormone blockers

- Have you got any experience of hormone blockers?
- What do you know about them? Where did you get your information?
- How do you feel about them? How has it been accessing them?

Hormones

- What is your experience of hormone therapy (if any)?
- What do you know about them? Where did you get your information?
- How do you feel about them? What has changed? What have/haven't they been able to do?

Surgery

- Have you had any experience of surgery?
- What do you know about it? Where did you get your information?
- How do you feel about it?
- Can you describe the recovery from surgery?

Aftercare

- How is it now (if) undergone gender confirming surgery?
- What support do you have?

Detransition

- What are your thoughts about detransitioning?

Autonomy

- How did you feel about your relationship with professionals?
- What was/is your experience of having control over your body in health care?

Private

- What are your experiences of private health care? If none: what do you know about it?
- Can you describe an example of a negative experience in a healthcare setting?
- What about a positive experience?

Prejudice/discrimination

- Have you ever experienced any prejudice or unfair treatment in healthcare settings?
- Are you able to describe it?

Mental health

- Has your mental health been impacted by gender identity? Or vice versa
- If so, what do you find helpful in supporting your mental health?
- Any experiences of counselling? Have you experienced any barriers to accessing mental health care? What's your experience of CAMHS and other mental health services?

Sexuality

- How do you experience your sexuality with relation to your trans identity?

Sexual and reproductive health

- What has been your experience of sexual health care as a trans person?
- What barriers have you experienced? Have you found anything helpful?
- What are your thoughts about pregnancy/having children as a trans person? What (if any) barriers have you experienced?
- What experience did you have of LGBT education?

Other factors

- What impact do other factors in your life (Ethnicity? Disability? Class? Religion?) have on your healthcare experiences?

Online/community

- What is your experience of support? Do you use online networks/communities?
- What is your experience of (young people's) face-to-face and online groups?

Public debate/media

- What are your thoughts about current public interest in trans young people accessing health care?

Future/change/reflection

- How have you changed since starting this journey? What do you see next for yourself?
- What do you feel would be useful as an extra resource going through your journey?
- How would you like to see healthcare services change in the future? How do you think this can best be done?
- What advice would you give a GP or other health professional? Teachers? Parents?
- What advice would you give a young trans person?
- Anything you want to add?

Appendix 3 Parents and carers interview: topic guide

Personal journey

1. As a mom/dad/carer/sibling of a young trans person, what are your experiences? Can you talk me through your journey?
2. When did you realise that your child/sibling might be trans/gender diverse? Can you remember how you felt at the time?
3. What were your ideas about being trans/gender non-conforming before that? And now?
4. What are your main concerns in relation to the care that your child is receiving?
5. How has your child's social transition been for them/yourself/your family?

Experiences of health care

6. Can you remember the first time your child's gender identity was discussed with a health professional? How was that?
7. As a mom/dad/carer/sibling of a trans young person what kind of support was/is there for you within the health care system? What kind of support would you find useful?
8. How helpful have you found the health professionals your child has seen in relation to gender identity? How helpful were they for you as a mom/dad/carer/sibling of a trans/gender-diverse young person?
9. What are your views on the support young people receive before entering specialist care?
10. What are your experiences with GPs?
11. What role do the GPs play in providing care to trans and gender-diverse young people?
12. What do you think is important for GPs to be aware of when it comes to trans/gender-diverse young people?
13. What are your experiences with CAMHS?
14. What are your experiences with GIDS?
15. What are your views on the long waiting list?
16. What do you think should/could be done in the meantime?
17. How do you think a trans/gender-diverse young person experiences health care? Health care professionals?
18. Can you describe a time when your needs or the needs of your child were not met in health care settings?
19. Do you have any examples of positive experiences in health care?

20/21. What are your experiences of private health care? If none: what do you know about it?

22. What are your experiences of discussing fertility preservation options? If none: have you thought about this aspect?

Discrimination and barriers to care

23. Do you think young trans and gender-diverse people face any biases in health care? What about their parents?
24. What do you think could be done in health care to combat discrimination of trans people?
25. What are the major barriers to providing good care for trans young people?
26. What do you think is most important to young trans patients when accessing health care?

27. What is most important to you, as a parent/friend/relative?
28. What do you think about the levels of choice/autonomy that young trans people have in health care?

Information

29. Where do you get information about gender identity and being trans? How about gender-affirming care?
30. How did you first learn about different terms and identities related to gender diversity?
31. What do you think about the information available to you? What is the role of the internet?
32. What do you think about the information available to young people on trans health and gender identity?

Future

33. How can health care be improved for trans and gender-diverse young people?
34. What resources would you like to see developed in the future?
35. How can access be improved for young trans and gender-diverse people? What about those who come from marginalised backgrounds/experience multiple inequalities based on their race, class, ability, sexuality etc.?
36. What advice would you give to doctors and nurses working with trans young people?
37. What advice would you give to parents/carers of young trans and gender-diverse people?

Public debate

38. What are your thoughts on the current interest in trans-issues in the public debate?

……………………………………………………………

39. Is there anything we haven't talked about you wanted to add?

Appendix 4 Evaluation schedule

Introductions

- Go round the group (participants can also give pseudonym, no need for real name if not comfortable sharing); safeguarding, confidentiality, anonymity, General Data Protection Regulation/ data protection

Brief website run through

- Screen share

Design and layout

- What do you think about the Healthtalk website design? Layout? How it's set out? Colours? Feel of the website?
- Is there anything you would change?
- How easy to navigate – was it intuitive? Could you find information easily or areas that could be better?

Topics

- Do you have any favourite topics?
- What topics (if any) surprised you?
- What topics were most useful? What topics were less useful?
- Any topics you disagreed with/felt didn't quite fit on the website?
- Any topics missing?
- What do you think about the way they are organised? Clusters helpful?
- How relevant/helpful/useful are the topics to your life experience?

Representation

- How well do you think the content represents the experiences of the trans community AND parents?
- How well do you think the content represents trans health care in the UK?
- What do you think about the diversity of voices/experiences? Any experiences missing?

General content

- What do you think of the names, topic titles, sub-themes?
- What do you think of the overview clip?
- What do you think about the information included? Old? New? Wrong/out of date?
- What do you think about the clips? Video, stock footage, written?
- How well could you identify/relate to the experiences?

Accessibility

- Easy/difficult to use?
- What do you think about the clips, easy to follow?
- Spacing, difficult to read?
- Disability/accessibility issues?

Glossary, resources, credits

- Any comments/things you want to share?

Dissemination/promotion

- Who needs to see it?

Appendix 5 Evaluation feedback on the design, navigation, colours and accessibility of the resources

Evaluation participants first gave feedback on the design, colours, navigation, layout and accessibility of the resources. There were many positive comments on the professionalism of the website, with feedback saying it looked 'formal but not scary' and 'It looks like it's coming from an authoritative source rather than this is just a blog someone's made which I feel like is a good thing. It does seem like it's well researched and well developed'.

Many respondents said that the design of the website was accessible to users with different needs with positive feedback on text size, font and clarity of the resources. Most complimented the navigation of the website, describing it as 'user friendly' with the grouping of the subsections and topics on the left-hand side complemented on:

> *I wasn't having to think very much it feels like it's almost a book, so that makes it very intuitive … you're not going through a funnel of 'we'll send you to wherever we think you need to be' – it's very transparent, this is what we have, what do you want to read next?*
> *I like the fact its got the list down the side so I don't have to trawl through. I can click what bit I want to look at. It has to be user friendly for me and that is easy because it tells you all the different sections.*

The majority of respondents commented on liking the visual content of the resources: 'good to have videos to break up the text … easy to read for somebody who gets overwhelmed'.

There was also feedback on the colours of the website with participants describing it as 'not too glary' and 'doesn't strain your eyes'. A young person with autism felt that the resources had a

> *soothing colour palette, it puts you at ease which I appreciate because a lot of similar websites will use bold colours … but often that can mean its hell for people to look at for any extended period of time.*

Suggestions for improvements in design

At the same time, there was also feedback on improvements that could be made on the website design. For example, several participants had problems with using the resources on their mobile phone; they also found where the resources were listed on the A–Z not intuitive and felt they should be under 'T' for transgender. While some people liked the stock footage with video clips, others felt that the stock footage was 'annoying'. One participant did not like the art background in the parents' site for audio clips

> *didn't know what that was and wasn't really a fan of the art style – for the overview it cut between that and real clips and I think a silhouette with a name would be better. I'm just not a fan of the art style.*

Some commented on the video editing with pauses and cuts to different parts of an interview that felt.

> *a little unnatural … where there was a long silence … there was one that I was watching and I was like oh it's over and I started scrolling away and then it kept going – the gap was longer than I was expecting*

One person felt the donation button and wording around this was not helpful or encouraging. Some felt that while the colours overall were good, that the A–Z bar needed to be a darker colour/differentiated.

A few people felt that the grey-blue writing on the site was a bit difficult to see and preferred a darker colour for readability.

More detailed feedback was given to DIPEx, who run the website. Below you can see the changes that were made for the launch and dissemination of the resources.

Appendix 6 Health professional interview composition

(cited in Mikulak *et al.*, p. 942)[34]

BOX 1 Participants

Participant ID	Profession	Gender
HP1	GP	Cisgender male
HP2	GP	Cisgender female
HP3	Oncologist	Cisgender male
HP4	Practice nurse	Cisgender female
HP5	GP	Cisgender female
HP6	GP	Trans female
HP7	Counselling professional	Trans female
HP8	GP	Cisgender female
HP9	Psychologist	Cisgender female
HP10	GP	Cisgender female
HP11	Mental health practitioner	Cisgender female
HP12	Psychiatrist	Cisgender male
HP13	Psychologist	Cisgender female
HP14	Counselling professional	Non-binary
HP15	Psychiatrist	Cisgender female
HP16	Specialist registrar	Cisgender female
HP17	GP	Trans female
HP18	Voice therapist	Cisgender female
HP19	Endocrinologist	Cisgender male
HP20	GP	Cisgender female

HP, health professional.

Appendix 7 Content modifications to the Healthtalk sites after evaluation

The following list contains the content modifications made to the sites based on feedback from evaluation participants. Some suggestions indicate valuable future research which is beyond the scope of this study (see *Chapter 10*). For suggestions that were possible, modifications to the content were made by the team and changed on the website by DIPEx, who run the Healthtalk site. DIPEx also made many further technical changes to the sites on clip errors, broken links, adding important links and other errors.

- Missing experiences: people felt that homelessness and severe poverty were missing from the young person's site:

  > *Is there anything for people on the site who come out and lose support from their families? it's a big part of the community, being abandoned by family*

  While none of our participants were homeless at the time of interview, we did have participants talk about hardship and poverty and being homeless in the past. We reviewed the content and emphasised this further on the site, and added a subsection on being made homeless with information/resources from a homeless charity. We feel this would be an important and valuable follow on/future research project (see *Future research* in *Chapter 9*).

- Experiences of those in care or care leavers were not on the site. While none of our participants were in care or a care leaver, we agree this would be a valuable addition to the site. Again, we have suggested this as a future research direction in *Chapter 10*.
- Feedback suggested that conversion therapy and a link to a resource was not particularly visible on the site, and needed to be visible due to its topical nature. We added a reference on the site with a resource link in 'Mental health services, psychological therapies and counselling'.
- People commented that it was not clear whether actors were involved in the study and had looked for this verification. Verification that actors were used in this study for clips was added to the site (on the *Overview*/first page).
- One person who had recently de-transitioned felt that while it was helpful to see re-transitioning/de-transitioning mentioned on the site, they would have appreciated more on this subject. However, they were keen to caution that those stories were often 'weaponised' by groups who use examples of detransition to withhold and lobby against trans youth health care and rights. In response to this feedback, we added a subsection on de-transitioning/re-transitioning and made existing experiences of multiple transitions clearer. We also concur that this warrants a separate project to understand the numerous complexities of detransition (see *Chapter 10* for more on this).
- Eating disorders among trans youth was not visible. While this experience was in the youth site, we reviewed the content and made this more visible/easy to find.
- Feedback suggested there was a lack of diversity in the parent site – including no trans parents, or parent of colour: parenting is so diverse but on the parenting site it felt like I was seeing a lot of white middle class mothers and that is a bias in how we are thinking of parenting responsibilities. It was disheartening to see that but part of that might be who is represented by face, when I dug into it I was like oh there are fathers here and there are probably people here who are not white, but I'm having to pay attention to see that that's there.

  There are parents themselves of trans people that are not cisgender right? It felt like I was only seeing the perspective of cisgender parents. There were multiple attempts to purposively recruit for minority ethnic parents to come forward and more diversity in parenting gender. This has been reflected on by the team when we set up the TPOC youth panels. Again, future projects understanding trans parenting perspectives as well as TPOC parents would be very valuable, and we have added this to our future research suggestions in *Chapter 10*.

- Feedback suggested that abusive relationships (intimate partner violence) were missing from the website. As this was a key part of one participant's experiences of relationships (which featured in their extract), we reviewed the content and added further content to the topics of consent and support (in relationships) where this featured in the site.
- Feedback from one participant was that information was missing on siblings and grandparents and how they feel. Initially, the researcher recruited for families including other members, only parents/carers came forward in a target sample size of 20. It was therefore decided to do these experiences justice, and parents/carers were the main focus. Sibling and grandparent experiences warrant a distinct project in their own right.
- While the comprehensiveness of the resources was appreciated, people felt that each summary had a lot of information to go through. Suggestions included clickable bullet points/sections/drop down sections at the top of summaries because of the amount of information. DIPEx are currently reviewing the technicalities of doing this.
- It was felt that on the young person's site, the bullet points only refer to education 'not everyone over the age of 18 years is in education' – clarification of this was added in relevant topic summaries.
- Add a definition of asexual in the glossary.
- Glossary needs breaking up with different font and spacing 'difficult to differentiate between the entries' – this was changed in response.
- More explanations for acronyms were needed in the text as these were not always clear. These text changes were all made.

EME
HSDR
HTA
PGfAR
PHR

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