Study protocol: navigating access to gender care in Ireland—a mixed-method study on the experiences of transgender and non-binary youth

Seán Kearns, Catherine Houghton, Donal O’Shea, Karl Neff

ABSTRACT

Introduction There has been a global increase in demand for gender-specific healthcare services and a recognition that healthcare access is complex and convoluted, even in countries with well-developed healthcare services. Despite evidence in Ireland supporting the improvement in physical and mental health following access to gender care, little is known about the local healthcare navigation challenges. Internationally, research focuses primarily on the experience of service users and omits the perspective of other potential key stakeholders. Youth experiences are a particularly seldom-heard group.

Methods and analysis This study will use a sequential exploratory mixed-methods design with a participatory social justice approach. The qualitative phase will explore factors that help and hinder access to gender care for young people in Ireland. This will be explored from multiple stakeholders’ perspectives, namely, young people, caregivers and specialist healthcare providers. Framework analysis will be used to identify priorities for action and the qualitative findings used to build a survey tool for the quantitative phase. The quantitative phase will then measure the burden of the identified factors on healthcare navigation across different age categories and gender identities (transmasculine vs transfeminine vs non-binary).

Ethics and dissemination This study has been approved by St Vincent’s Hospital Research Ethics Committee (RS21-019), University College Dublin Ethics Committee (LS-21-14Kearns-O’Shea) and the Transgender Equality Network Ireland’s Internal Ethics Committee (TIECSK). We aim to disseminate the findings through international conferences, peer-review journals and by utilisation of expert panel members and strategic partners.

INTRODUCTION

Language and terminology in the field of gender care is dynamic and ever evolving. See table 1 for a brief overview of terminology used in this protocol.

Internationally, the incidence of people seeking gender care is increasing while the age of referral to gender services is decreasing.1 The reason for this is unknown, but it may be linked to the global improvement in rights for gender non-conforming individuals and increased visibility in society.2 As more people feel enabled to seek gender care, referral rates to services have increased more than 10-fold over the last 10 years.3 4

The health needs of people who are transgender or non-binary are nuanced and a wider spectrum of gender diversity is being seen. What is clear is that as a group, transgender or ‘trans’ people tend to have more complex care needs than the general cisgender population5 and gender care is often more involved than just providing endocrine services. Therefore, a multidisciplinary approach is likely to be needed in many people in order to deliver optimal care. This is especially true for younger cohorts to safely facilitate gender exploration.

The complexity of healthcare systems can be a major barrier for people seeking gender care. Other barriers such as social adversity,6 7 geographical location,8 the complexity of clinical need9 and cost may present further barriers to accessing care.10 Some of these may be particularly pertinent to younger
people. In addition, the acceptance of family members and the knowledge of healthcare providers are crucial in young people’s healthcare navigation. 11 12

One specific domain of need is mental health. Transgender and non-binary people have a higher burden of mental health needs than their cisgender counterparts. 13 14 The negative impact of gender dysphoria, discrimination and victimisation on mental health and psychosocial functionality is well documented in the literature. 15–17 This higher burden of mental health needs includes a greater incidence of complex needs and dual diagnoses, as well as higher rates of suicidal ideation and attempted suicide. 18 In Ireland, transgender participants were 75.6% more likely to end their own life than gay males or lesbian females (who were already three times more likely than their heterosexual/cisgender peers). 19

However, the needs of the trans population are not only needs related to mental health. A systematic review and meta-analysis of 29 studies concluded that transgender people displayed a poorer quality of life than the general population. 20 This can be due to social adversity (both at home and in wider society), an inability to engage in the world of work or education, and impaired occupational functioning.

Cohort and longitudinal studies demonstrate that mental health outcomes improve following engagement with gender services. 20 21 A positive correlation can be seen between transitioning and mental health, life satisfaction and job satisfaction. 22 For some people, transitioning is purely a social process, but for others, medical interventions such as hormone therapy or surgery will be part of their transition.

Hormone therapy can improve quality of life scores in transgender individuals 23–29 and gender-specific surgeries have similar effects. 29–35 In an Irish study, 75% of transgender adults noted an improvement in mental health and well-being following medical transition. 36 Similarly, a longitudinal study in Amsterdam exploring the effectiveness of medical interventions among youth found that medical transitioning improved the well-being of trans youth to a degree that put them on a par with cisgender counterparts. 29 Access to gender healthcare can be life-enhancing and improve the mental health and life satisfaction of individuals, irrespective of age.

The proposed research aims to provide information about access and utilisation of gender care in Ireland with a specific focus on transgender and non-binary youth. Youth as per the WHO is classified as 12–24year olds. 35 However, due to the often delayed experiences of coming out as gender diverse, delays in seeking gender care and the limited services for under 18 in Ireland, the authors felt it reasonable to extend our definition of youth to include 12–30year olds.

This study will identify important barriers to care across different age brackets and from multiple stakeholder perspectives. Understanding the experiences youth

Table 1  Key terms in transgender literature

<table>
<thead>
<tr>
<th>Key terms in transgender literature</th>
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<tr>
<td>Transgender/transgender</td>
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<tr>
<td>‘Transgender’ is the more commonly used umbrella term to describe the gender of a person whose gender identity or gender expression differs from the normative societal expectations of the gender they were assigned at birth. 86 Transgender became used colloquially among queer communities in 1971 and the shortened term ‘trans’ or ‘trans’ as is contemporary as 1996. 9 Transgender individuals may identify in a binary manner, meaning, if their assigned gender was female, they identify as male (sometimes documented as ‘FtM’), and vice versa (‘MtF’). The person may use the term ‘trans man’, ‘trans woman’, ‘transgender man’ or ‘transgender woman’. Assigned female at birth (AFAB) and assigned male at birth (AMAB) are the current preferred terms used vs ‘FtM’ or ‘MtF’.</td>
</tr>
<tr>
<td>Non-binary</td>
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<td>‘Non-binary’ is another umbrella term that refers to individuals who do not identify as exclusively male/masculine or female/feminine. 10 11 A non-binary individual may identify with neither of these, fluctuate between the gender binary, identify with both, or reject all. Non-binary people may identify as non-binary, gender-fluid, gender flex, gender non-conforming, gender non-normative or genderqueer. More recently, there has been an increase in quantitative research of people rejecting the binary. There is inherent overlap between trans and non-binary identities with some individuals having affinity to one term alone or both (eg, a non-binary person may also identify as trans).</td>
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<tr>
<td>Cisgender</td>
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<td>The term ‘cisgender’ (from the Latin cis-, meaning ‘on the same side as’) can be used to describe individuals who possess, from birth and into adulthood, the male or female reproductive organs (sex) typical of the social category of man or woman (gender) to which that individual was assigned at birth. Hence a cisgender person’s gender is on the same side as their birth-assigned sex, in contrast to which a transgender person’s gender is on the other side (trans-) of their birth-assigned sex. 86 87</td>
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<tr>
<td>Gender dysphoria</td>
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<td>Gender dysphoria is a condition of psychological distress due to an incongruence between a person’s gender and the gender that they were assigned at birth. 37 A person may be gender non-conforming his/her entire life without experiencing gender dysphoria. If one does experience dysphoria, then this can be alleviated by gender affirming medical interventions, such as gender affirming hormone therapy and gender affirming surgery. Both binary transgender individuals and non-binary individuals may benefit from medical intervention. 87 As well as medical intervention, gender affirming interventions based on social transition (changing their gender expression in social situations to align with their gender identity) and psychosocial support can effectively remEDIATE gender dysphoria. 88 89</td>
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<tr>
<td>GnRH blockers</td>
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<td>GnRH blockers are medications used to suppress endogenous sex hormone secretion determined by a person’s genetic/gonadal sex. These medications will inhibit the production of testosterone and oestrogen. These medications are used in isolation to ‘delay’ puberty in young adolescents and sometimes are used in conjunction with other medications into adulthood to achieve specific gender goals. 37</td>
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</table>

Note: This study will identify important barriers to care across different age brackets and from multiple stakeholder perspectives. Understanding the experiences youth
have in accessing gender care will shape evidence-based recommendations for improvement of service provision and policy formation.

What is gender care?
Gender care encompasses a variety of services that seek to alleviate gender dysphoria, including support with social transition, hormone therapy, surgery and access to mental health services. Every person has a unique transition process that may involve all or none of these elements.36

From a medical perspective, individuals may seek out anti-androgen therapy (blockers) or cross-sex hormones to alleviate their gender dysphoria.37 They may also seek a referral for surgical procedures including genital surgery, chest surgery, and facial and neck surgeries.38

Access to mental health services to evaluate gender dysphoria and ongoing mental health needs is recommended for all.37 This population may benefit from access to specialised voice and communication therapy, healthcare navigators, reproductive advisors, legal advisors, social workers and occupational therapy to optimise their care and support their transition.39

All of the above services are covered under the term ‘Gender Care’. In order to access gender care, often transgender or non-binary people often gain access through their local primary care team and will be referred to a specialist multidisciplinary gender centre, or to individual single discipline services.

Access to gender care
Access to healthcare is compounded by a myriad of factors midst the healthcare navigation process.10 These factors can be clustered under the following headings: personal, environmental, economic, biomedical and psychosocial.

Reluctance to disclose gender identity to others is frequently documented as a personal barrier to seeking gender care as well as previous experiences of stigma, discrimination and refusal of care.6 7 41–46 Lack of services, lack of gender specialists, waiting times and geographical burdens have been identified as environmental barriers to accessing care.47–50

Moreover, the cost of care and prohibitive insurance policies have been reported as economic barriers in healthcare access.51 52 Biomedically, negative experience with healthcare providers and lack of training for providers is a major barrier, with many individuals feeling forced to be educators to their health providers.44 53–55

In contrast, comfort with a family doctor was associated with positive outcomes and increased health and access to care.56 Having psychosocial supports such as LGBTQ (lesbian, gay, bisexual, transgender and queer) groups, family support, a healthy relationship and friends have been identified as enablers to healthcare and a barrier if lacking.54 55

For youth, there are additional factors impacting access to services such as parental support and the family unit becoming more involved in the care plans. Regarding youth, there are ongoing ethical dilemmas of access to gender care for those without parental support.56 While the experience of adults accessing gender care is well reported, less research explores the unique challenges that face transgender and non-binary youth with navigating healthcare.57

The Irish context
In Ireland, there is a paucity of research exploring the landscape and the experiences of accessing gender care. Research from Europe, the UK and North America may not easily translate to the Irish landscape due to significant differences in health systems, cultural and societal expectations, models of care and legal processes.

In our scoping activity, we only identified one Irish study directly related healthcare access for transgender adults in Ireland.58 A formative piece commissioned by the Equality Authority of Ireland, it is limited by a small sample size (n=15) and a vastly different cultural landscape from the current context as it was completed in 2004. The initial barriers to access in Ireland were determined to be geographical accessibility, lack of information, lack of professional awareness, lack of family services and limited or inappropriate service provision.

The most prominent trans-specific research completed in Ireland investigates mental health and well-being. McNeil et al34 explored the mental health challenges and improvement in mental health post access to transition-related care.34 Both of these studies focus solely on adult populations and omit any perspectives from other stakeholders.

In the Irish context, we know that barriers to healthcare access exist but demand deeper exploration, mental health needs are improved post transitioning and the number of people needing gender services are rising year on year. Furthermore, it is evident that transgender youth are a seldom-heard voice among the Irish research platform and that little public patient involvement or co-production has been used in research projects thus far. Therein lies the need for more extensive research in this field.

Study aims
1. To explore factors that help and hinder access to gender healthcare for young people in Ireland from multiple stakeholders’ perspectives, namely; young people, caregivers and specialist healthcare providers (PART 1—QUAL).
   - To determine the current landscape and referral practices of gender care in Ireland.
   - To identify enablers and barriers to accessing gender care from multiple stakeholders’ perspectives.
   - To consider and evaluate the perceptions, needs and experiences of stakeholders regarding healthcare navigation of gender care.

2. To measure the burden of the identified factors on healthcare navigation across different age categories and gender identities (transmasculine vs transfeminine vs non-binary) (PART 2—QUANT).
To investigate what extent of impact barriers and enablers have on healthcare navigation.

To compare the burden of barriers on healthcare navigation across gender identities and age cohorts (12–16, 16–24 vs 24–30).

3. To develop recommendations to inform policy, clinical practice and intervention development.

**METHODOLOGY AND METHODS**

**Study design**

A sequential exploratory mixed-methods design with a participatory social justice approach will be used.

This design will best answer the research question, aims and objectives while ensuring the populations’ voice is central to the project. As a sequential design, we will conduct the qualitative phase, followed by the quantitative phase (see figure 1). The qualitative phase will identify the factors that impact healthcare accessibility from multiple stakeholders’ perspectives through individual semistructured interviews. Due to the study design and our research priorities, the qualitative strand will be more heavily weighted as little is known about research in this area, especially with regard to our population’s age, and within the Irish context. Qualitative inquiry will allow the generation of rich data detailing individuals’ experiences and perceptions. The qualitative data will then be used to develop as survey tool, created to measure the extent of factors on healthcare access and to promote the generalisability of results.

**Theoretical underpinnings**

The paradigm of this research will be set in the transformative paradigm. This paradigm emerged because of dissatisfaction with research conducted within paradigms that were perceived to be irrelevant to or misrepresented of, the lives of people who experience oppression.

The transformative approach provides a systematic framework with a special interest in detailing and mitigating against power dynamics to apply to conceptualisation, data collection and data analysis stages of this current study. The authors chose this paradigm as it champions patient and public involvement and commits to advancing social change for oppressed populations. See online supplemental file 1 for Merten’s list of 10 criteria for mixed-methods working within the transformative paradigm and how this study endeavours to meet the criteria.

Merriam defined the theoretical framework as the researcher’s lens with which to view the world. For the purpose of this project, we will be using ‘the gender-affirming’ model as the theoretical framework. This framework posits that (1) gender development is natural, not pathological; (2) gender presentations are diverse and varies across cultures; (3) that biological, developmental, social and cultural factors can influence gender development; (4) gender may be fluid; and (5) pathology...
if present often stems from social adversity. This theoretical framework compliments our theoretical paradigm as it does not pathologise gender and aligns with the research teams axiology.

The conceptual framework is the researcher’s understanding of how the research problem will be best explored, the specific direction the research will have to take and the relationship between different variables in the study. Ryvicker derived a behavioural-ecological framework in order to help to describe healthcare navigation as realised access to healthcare becomes more involved and individuals require more advanced skillsets to achieve care. We discussed this model with our expert panel and key stakeholders and found it provided a structured approach to explore navigating gender care. We developed our interview guides (see online supplemental file 2) based on this model and the key topics proposed and will use this model to support data analysis.

This model proposes that while individual predisposing, enabling, need and health belief characteristics influence realised access to care. Individual characteristics are only one component to understanding enabling and constraining factors involved in healthcare utilisation. Neighbourhood demographics, social environment, built environment, healthcare environments and provider factors all play an instrumental role in health practices, healthcare navigation, realised access and healthcare outcomes.

**Patient and public involvement: expert panels**

In line with Mertens’s transformative framework, this framework proposes that a marginalised community should have input into the conceptualisation of the study as well as the design and data analysis. In order to include the voices of as many key stakeholders as possible, an expert panel of transgender and non-binary young people has been assembled to co-produce research questions and advise on each phase of the project.

Ten young people have agreed to be a part of the expert panel varying in gender identities and geographical location. Meetings are held on Zoom and there is a qualified youth worker on each call to provide links to additional support services if needed.

This group have and will be asked to provide consultation on a number of areas, such as (1) language and terminology, (2) chosen data collection instruments, (3) review of interview guides and topic inclusion, (4) interpretation of qualitative results and coding, (5) co-design of survey tool, (6) dissemination of results and recommendation of interventions, (7) development of plain language summaries.

While the expert panel will guide the research, other key stakeholders who have a vested interest in the area will also contribute their feedback for consideration by the panel and research team. Notably, the National Gender Service, a transgender support group and an LGBTQ youth service. Partnership with each of these groups has been established.

**QUALITATIVE PHASE**

**Participants and setting**

Participants for the qualitative phase will be from three key stakeholder groups, namely, transgender and non-binary young people, caregivers and healthcare providers working in the area of gender care (see table 2). The study will include participants from any area of Ireland.

**Transgender and non-binary youth**

GnRH blockers are available under 16 years old in Ireland. Cross-sex hormones and gender-related surgeries are generally not available for people under 16. For the purposes of the qualitative aspect, we will be interviewing up to 10 transgender young adults ages 18–30 years old. We believe that younger adults will be able to adequately recall their experiences from when they were 16 or younger. These will be recruited from (1) those who present at gender clinics, (2) through flyers distributed by LGBTQ and trans-specific support groups, and (3) snowball sampling from existing participants.

**Parents/caregivers**

We will be interviewing up to 10 parents or primary caregivers of transgender youth. These caregivers do not need to be linked to the transgender/non-binary youth participating in interviews. These will be recruited from (1) those who present at the gender clinic with their young person, (2) youth in the study who give permission to have their caregivers contacted, (3) flyers distributed by LGBTQ and trans-specific support groups, and (4) snowball sampling from existing participants.

**Healthcare providers**

We will be interviewing up to 10 healthcare providers who provide gender care. This will include endocrinologists, psychologists, psychiatrists, primary care physicians, social workers, speech and language therapists, and clinical nurse specialists/healthcare navigators. These will be recruited from (1) multidisciplinary team at National Gender service and (2) snowball sampling from recruited participants.

**Sampling**

Snowball sampling with maximum variation sampling will be used here to ensure that we recruit participants who have had a host of different experiences, whose gender identities vary and come from different backgrounds. We want to include participants who have been through the public system versus the private system, include participants who have received care versus those who are waiting to be seen, we want to include participants who have received surgical interventions and participants who engage with peer-supports versus those who do not.

**Data collection**

Data will be collected via individual semistructured interviews. These will be conducted by the lead researcher via Zoom, an online video platform. Data collection will be...
from May 2021 to May 2022. Interview guides included in the protocol (see online supplemental file 2).

**Data analysis**

The qualitative interviews will be recorded, transcribed, and coded using framework analysis. This is a form of qualitative analysis that creates matrices of prioritisation based on the participants’ perspectives. It was chosen as it serves to deliver results in a manner that prompts action and is most fitting with our transformative paradigm. It is a five-stage iterative process involving (1) familiarisation, (2) identifying a thematic framework, (3) indexing, (4) charting, and (5) mapping and interpretation. This process will be completed for each cohort from the qualitative strand and the results will be used to build a quantitative survey to assess for generalisability and further impact. The coding will be managed within NVivo software V.12.

**QUANTITATIVE PHASE**

**Participants and setting**

The participants will be transgender and non-binary youth. We know many transgender and non-binary youth do not seek gender care until later in life. Therefore, for the purpose of this strand, youth will be categorised as 12–30 years old. The survey tool will be available online.

**Sampling**

The quantitative strand will involve random sampling of transgender and non-binary youth. The sample size will be based on a 95% CI and a 5% margin of error. The average percentage of transgender and non-binary youth between 13 and 24 is 0.7% and the recent census (2016) has the 1133903 citizens aged 12–30 years old. This estimates 7937 transgender and non-binary youth nationally. Therefore, a necessary sample size will be 367 participants.

**Data collection**

Data will be collected by an online survey. The survey will be advertised at the National Gender Service to attendees and will be advertised by LGBTQ and trans-specific advocacy groups and peer support groups. Consultation has been agreed and stakeholder partnerships agreed. The expert panel of youth will assist with the dissemination of the survey to trans-specific online groups. This phase will be designed based on the results of the qualitative strand and assess self-reported healthcare navigation needs, enablers, barriers and perceptions of care. The tool will be piloted prior to rollout and designed in collaboration with the expert panel. Data will be collected from September 2022 to February 2023. Survey will be generated based on findings from qualitative strand and therefore cannot be added as supplementary data.

**Data analysis**

Quantitative data will be collected using Qualtrics software. Results will then be inputted into the Statistical Package for the Social Sciences (SPSS) V.26. Data will be cleaned and descriptive and inferential performed in line with the research question. This will be explored across different gender identities and age groupings. As our
definition of youth encompasses a vast array of ages, we will analyse our results through the lenses of three age cohorts: 12–16, 16–24 and 25–30.

Integration of qualitative and quantitative results

The integration will further be detailed in the analytic and interpretation level through Joint Display. Results will be displayed in table format including three columns. Column 1 will represent the exploratory qualitative findings as direct quotes. Column 2 will showcase the factors/dimensions interpreted from the qualitative findings and column 3 will show how the measures and factors form a new survey or scale.

QUALITATIVE RIGOUR

Rigour in qualitative research can be determined in many ways. Ultimately, the purpose is to establish credibility, confirmability, transferability and dependability.

In this study, maximum variation and snowball sampling will be used to ensure the most appropriate participants are identified. We believe that having participants with a broad array of backgrounds is vital in order to identify diverse experiences and reduce participant bias. In order to reach data adequacy, we will be looking to ensure that we have quantity in terms of thick description and quality in terms of rich description. We have initially set a sample size aim but have ethical approval to extend further, as needed.

Ethical conduct will be vital in developing researcher–participant trust. Ensuring the correct use of name, pronoun and gender identity will be crucial in establishing a relationship. Optional member checking will be used to confirm the accuracy of verbatim interview transcription prior to any analysis for a set period of time after the interview.

An audit trail will be used to document the step-by-step process in deriving the results. The use of Nvivo software will aid transparency. The team will invite a third-party researcher to analyse the audit trail and coding for a set number of participants. The expert panel will also be involved in the coding and interpretation of results. Triangulation from multiple data sources will be sought and tracked to show results and interpretations.

The authors as cisgender individuals need to mitigate their own biases and recognise their power roles. The lead researcher will be keeping a reflective diary during the process. The chosen paradigm stresses the importance of the population’s inclusion at every level and the expert panel’s role in study design and interview questions help at multiple stages to ensure rigour.

QUANTITATIVE RELIABILITY AND VALIDITY

The survey generated from the qualitative findings will be pilot tested for reliability (internal consistency, test–retest reliability, inter-rater reliability) and validity (content validity, construct validity, internal validity, external validity).

ETHICS

The qualitative phase of the study has received ethical approval from three ethics organisations: St Vincent’s Hospital Research Ethics Committee (RS21-019), University College Dublin Ethics Committee (LS-21-14Kearns-O’Shea) and the Transgender Equality Network Ireland’s Internal Ethics Committee (TIECSK). Ethical issues were considered prior to applying and were identified as follows: anxiety and distress of participants, exploitation, misrepresentation and confidentiality. To mitigate against these factors, a distress protocol will be in place for any sensitive conversations (see online supplemental material 3), the transformative research paradigm and utilisation of expert panel will work against any potential power imbalances and risk of exploitation and misrepresentation. A data protection plan has been enacted to ensure compliance with national standards of data protection and is outlined in the consent form.

Before consenting any participants, an information sheet will be given, ample time allocated to consider and all questions answered. Participants can withdraw at any time. Any adjustments needed for literacy or disability will be facilitated by the research team in consultation with the participant. For the qualitative phase, the participants’ identity will be protected by using pseudonyms, and any data that may identify an individual will be not be transcribed or coded. Pseudonyms will be used on all files and all transcripts. All interviews will be completed by a registered healthcare professional.

The quantitative phase will not include any identifiable information and will be an anonymous survey. An information section and consent to participate will be included and contact information to ask questions. The survey will be anonymous to allow as many people as possible to participate but an information sheet will be provided and participants will be asked to consent to their understanding and participation. The questions will be presented in English and should take approximately 30 min to complete.

DISSEMINATION

Impact is of the utmost importance to this project. This will be achieved through a number of strategies. This project is a doctoral project and is being completed through dissertation by publication and therefore up to five papers will be published of the study design and results.

Strategic collaboration has been made with LGBTQ organisations and the National Gender Service and a report of the key findings and recommendations will be disseminated to all parties.

The expert panel will be forming their own dissemination plan and this will include attendance and presentation
with the primary author at conferences and the formation of plain English summaries of results to be disseminated by LGBTQ organisations and the National Gender Service. The expert panel will also advise on recommendations for improvements in services and practice based on the results. This research will have a profound impact on the pool of evidence and will help to identify potential interventions to enact change. This could be a training programme for primary care teams who refer, a resource driven by gender specialists of what youth and families can do while on waiting lists or a number of other high impact initiatives.

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Patient consent for publication Not applicable.

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