

**Scottish Public Health Network (ScotPHN)**

**Health Care Needs Assessment of Gender Identity Services**

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## Preface

One of the founding principles of the NHS is that it exists to meet the many and varied healthcare needs of people. In the 70 years which the NHS has been responsible for this in Scotland, we have learned that to do so we must embrace and respect the rich diversity of communities and cultures that make up the Scottish population. This is what is meant when we say that the healthcare should be “person-focussed”, yet provided in a realistic way that can help sustain the NHS overall. Against this background, I welcome ScotPHN’s healthcare needs assessment for gender identity services in Scotland as it clearly seeks to help create a more sustainable service for Scotland that keeps the individual at the heart of the care being provided.

I am also aware that the way in which this report has come together is an example of how the new system for public health that is being created can work more effectively in the future. What started as a specific piece of work in NHS Greater Glasgow and Clyde was quickly identified as needing a more broad “best for Scotland” approach. In accepting this challenge ScotPHN was able to not only work with the existing, national network of gender identity services across Scotland, but also ensured that the essential contributions of the Third Sector agencies that work with and for those who need such service were identified and incorporated into the work from the outset.

I extend the warmest of thanks to Rachel Thomson, Jess Baker, and Julie Arnot who wrote the report. More broadly, I would also like to thank the many people from: the Third Sector agencies that helped shape the work and shared their own research and insights; my own Health Board who started the work and contributed to it significantly; and the National Gender Identity Clinical Network along with all those who provide gender identity services, whose contributions made it possible to expand the work across Scotland. Finally, I would like to thank the team at ScotPHN whose approach to creating and supporting collaboration allowed it to all happen.

I hope that this report is discussed and used widely in helping to develop sustainable gender identity services in Scotland. But I also hope it is seen for what it is: an example of realistic population health in practice.



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# Acknowledgements

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## Acronyms

<b>A&amp;A</b>	Ayrshire and Arran
<b>AEARP</b>	Adult Exceptional Aesthetic Referral Pathway
<b>AFAB</b>	Assigned female at birth
<b>AMAB</b>	Assigned male at birth
<b>CAMHS</b>	Child and adolescent mental health services
<b>D&amp;G</b>	Dumfries and Galloway
<b>FtM</b>	Female to male
<b>GG&amp;C</b>	Greater Glasgow and Clyde
<b>GIC</b>	Gender identity clinic
<b>GRP</b>	Gender Reassignment Protocol
<b>HCNA</b>	Healthcare needs assessment
<b>LGBT</b>	Lesbian, gay, bisexual and transgender
<b>LGBTQ+</b>	Lesbian, gay, bisexual, transgender, queer/questioning and others
<b>MtF</b>	Male to female
<b>NGICNS</b>	National Gender Identity Clinical Network for Scotland
<b>NSD</b>	NHS National Services Division
<b>SALT</b>	Speech and language therapy
<b>SIMD</b>	Scottish Index of Multiple Deprivation
<b>STA</b>	Scottish Trans Alliance
<b>WPATH</b>	World Professional Association for Transgender Health

## Executive Summary

Individuals who identify as transgender (or trans) have a gender identity that differs from the sex they were assigned at birth. Some trans people may need specialist healthcare services to support them with their gender identity, or to access gender reassignment treatments. In Scotland, such services are provided by four specialist adult gender identity clinics located in Glasgow, Edinburgh, Aberdeen, and Inverness, and one specialist young person's clinic located in Glasgow. Each clinic differs considerably in how it is run and what services it is able to offer, but all treatment should be provided according to the Scottish Gender Reassignment Protocol (2012). Additional support for trans people is often provided by the voluntary sector, sometimes in partnership with the NHS.

Demand for specialist gender identity services has been increasing over the past several years in Scotland as it has elsewhere in the world, resulting in long waiting times, but there has been no clear analysis of why this was happening, how it was impacting on the trans population, or what was likely to happen to demand in the future. This Healthcare Needs Assessment aimed to better understand how existing services across Scotland relate to the needs of service users, and how they might be improved to respond to current and future demand, using a variety of methods including data analysis and interviews to engage with service providers and the trans community.

### **Data from Gender Identity Clinics**

While it was not possible to find a precise estimate of the number of trans people in Scotland, the most commonly used figure is 0.5% of the population, which would be just under 24,000 adults. The number of trans people accessing services at Scottish Gender Identity Clinics is much smaller than this, around 1800 adults and 600 children over the four year period from 2014 to 2017. However, the number of referrals each year increased markedly across Scotland in this time. The largest increases were from 2014 to 2015, and though 2017 numbers were still higher than previous years this may be reaching a plateau. Further data for 2018 would be required to confirm this, as the rate of change is not completely predictable.

The average age at referral has fallen over time, and is currently 26 years for adults and 14 years for young people. More trans adults are accessing services from cities than rural areas, particularly Edinburgh, which is not seen with trans young people. It is likely this is related to trans adults relocating to areas where they know there are services and communities to support them.

## **Waiting Times for Gender Identity Clinics**

Nationally, waiting times for adult services have decreased over time, but this varies markedly by clinic with waiting times falling significantly in Edinburgh, being fairly consistent in Glasgow, and increasing in Inverness over four years. Waiting times for young people have increased over the same time period. It is not clear why clinics have seen such different trends in waiting times with the same degree of increase in patients, and further work would be useful to know whether any differences could be related to service design. The average waiting time to first appointment in 2016 was 260 days for adults, and 314 days for young people.

## **Changes in the Patient Population**

Interviews with gender identity specialists, third sector organisations, and other stakeholders identified that as well as simply increasing in number, the characteristics of the trans population presenting to services are changing. They reported an increase in the number of young people and non-binary people (those who do not identify as male or female), as well as an increase in the proportion of trans people who were still at the stage of questioning their gender identity.

## **Reasons for Increasing Demand**

A number of reasons for the overall increase in demand were suggested, including better service provision, positive changes in societal attitudes, and greater access to information on transgender issues through the Internet and social media, giving more trans people the vocabulary and confidence to self-identify. Service providers and other stakeholders felt that the increase in demand for services reflected an increase in the proportion of the trans population who felt able to present to services, rather than an increase in the underlying number of trans people.

## **Inequalities in Accessing Gender Identity Services**

There were potential inequalities in accessing gender identity services highlighted, particularly relating to geography, with a minority of Scottish health boards providing local gender identity services and third sector services also largely based in urban areas. Other inequalities related to gender identity (with non-binary individuals more likely to have negative experiences at clinics), presence of co-existing mental or physical health problems, and lack of financial means to travel or access private treatments.

## **Service User Views**

From a large survey of Scottish trans service users, the main concerns expressed about services were around long waiting times and the distress this

caused, and a perceived need to withhold information on gender identity, mental health, gender expression or sexuality for fear this would block or delay access to treatment. The current Scottish Gender Reassignment Protocol was not felt to be inclusive of non-binary individuals or supportive of an informed consent model. However, overall experience of treatment outcomes was largely positive, particularly for hormone treatment and surgery, and some service users described very positive examples of person-centred care.

### **Comparisons with Other Countries**

Comparing Scottish services to those in the rest of the UK and worldwide, the issues of trans service users in accessing healthcare and the recent increases in demand are shown to be very similar. The structure of Scottish gender identity services have much in common with those in the rest of the UK, though on some measures such as waiting times Scotland appears to be performing slightly better. However, in contrast with many countries who provide trans healthcare services, there are no surgical services for gender reassignment provided in Scotland, with all who need this requiring to be referred to NHS England.

### **Conclusions and Recommendations**

In conclusion, it is positive that the proportion of Scottish trans people presenting to specialist NHS and/or third sector services to access gender-affirming treatment is rising, but this has also increased pressure on services and led to long waiting times. While the increase in referral numbers may be reaching a plateau, there is still significant progress required to catch up with and maintain current levels of demand. Additionally, the characteristics of those accessing services are changing, and may not be met by current services. More young, questioning, and non-binary people are presenting, who may have differing requirements and expectations of services, requiring them to adapt their approach and become more flexible. There was no consensus among service providers on the best way to reshape services to better match these needs. A range of recommendations are made in this report covering: consideration of alternative care models including further involvement of multi-disciplinary teams, primary care and the voluntary sector; adaptation of services to the changing presentations of trans people; increased support for those on waiting lists; staffing increases to meet rising demand where required; strategies to reduce geographical inequalities in access to services; workforce development; increased data gathering; and review of the current national Gender Reassignment Protocol.

## What Does This Mean For Us?

A variety of positive aspects of current specialist gender identity services in Scotland were highlighted, alongside a number of limitations. Updating the model of care in these services, and using innovative approaches to reduce inequalities as recommended in this report, could help bring them more in line with the healthcare needs of the Scottish trans population now and in the future. Services should continue to strive to be person-centred, following an informed consent model to ensure all decisions around treatment are led by the personal goals of the individual.

It is recommended that there is detailed consultation with stakeholders about any proposed changes, with a strong focus on service user views and community engagement and empowerment, to design services which are acceptable to and appropriate for all Scottish trans people. It is our hope that this could be led by and build on the work in this area already undertaken by the National Gender Identity Clinical Network for Scotland, possibly through stakeholder events after initial consideration of the recommendations by the group. Third sector partners including the Scottish Trans Alliance also plan to publicise and distribute this report to the trans community through their communications networks, to raise awareness of the findings and continue the existing dialogue between service users and service providers.

## Definitions and Terminology

A variety of terms exist to describe trans people and people's gender identity. These terms depend on the cultural setting and are evolving over time(1). A useful overview of the terms relevant to Scotland can be found on the [Scottish Trans Alliance](#) website(2).

This report uses "trans" people as an umbrella term for people with a range of non-conforming gender identities or gender identities that differ from societal norms(1)(2). Other common terms encountered in carrying out this work are also used, including trans man (a trans person who currently identifies as a man (3), trans woman (a trans person who currently identifies as a woman (3), and non-binary (a trans person who identifies as neither male nor female(4). Gender identity is an individual matter and different people will prefer different terms, so it is acknowledged that the terms used in this report may not be the most preferable for some trans people.

# Chapter 1: Introduction

## Background

Transgender people are a diverse population of individuals who have a gender identity that differs from the sex they were given at birth(1)(5); gender identity is defined as an individual's internal sense of being male, female, or another gender(1). Some transgender (or trans) people experience gender dysphoria. This is a condition in which an individual experiences distress because their gender identity differs from their assigned sex, and can range in severity(1)(6). Dysphoric patients report higher rates of psychiatric disorders than the general population, particularly depression and anxiety disorder(7).

The current version of the International Classification of Diseases (ICD-10) includes a category for gender identity disorders that is applicable to people with gender dysphoria within the 'mental health and behavioural disorders' chapter (8), though with the publication of ICD-11 in 2018 it will be moved to a proposed new chapter of 'conditions related to sexual health'(9). Equality legislation in the UK protects trans people from discrimination based on their gender identity, and this legislation may be subject to further development (10).

Some trans people may need specialist healthcare services to support them with their gender identity or to access gender reassignment treatments. These services could range from counselling, hair removal, and speech and language therapy (SALT), to hormone treatments and gender reassignment surgery(1). Gender affirming interventions have the potential to cost-effectively improve quality of life(11). Wylie *et al* provide a useful review of transgender clinical care, highlighting that hormone treatment and surgery is associated with increased quality of life and that post-surgical regrets are not common(12). It is noted that trans people will also require healthcare not related to their transition throughout their lives and that this must be culturally sensitive to their experiences, however that is outwith the scope of this work.

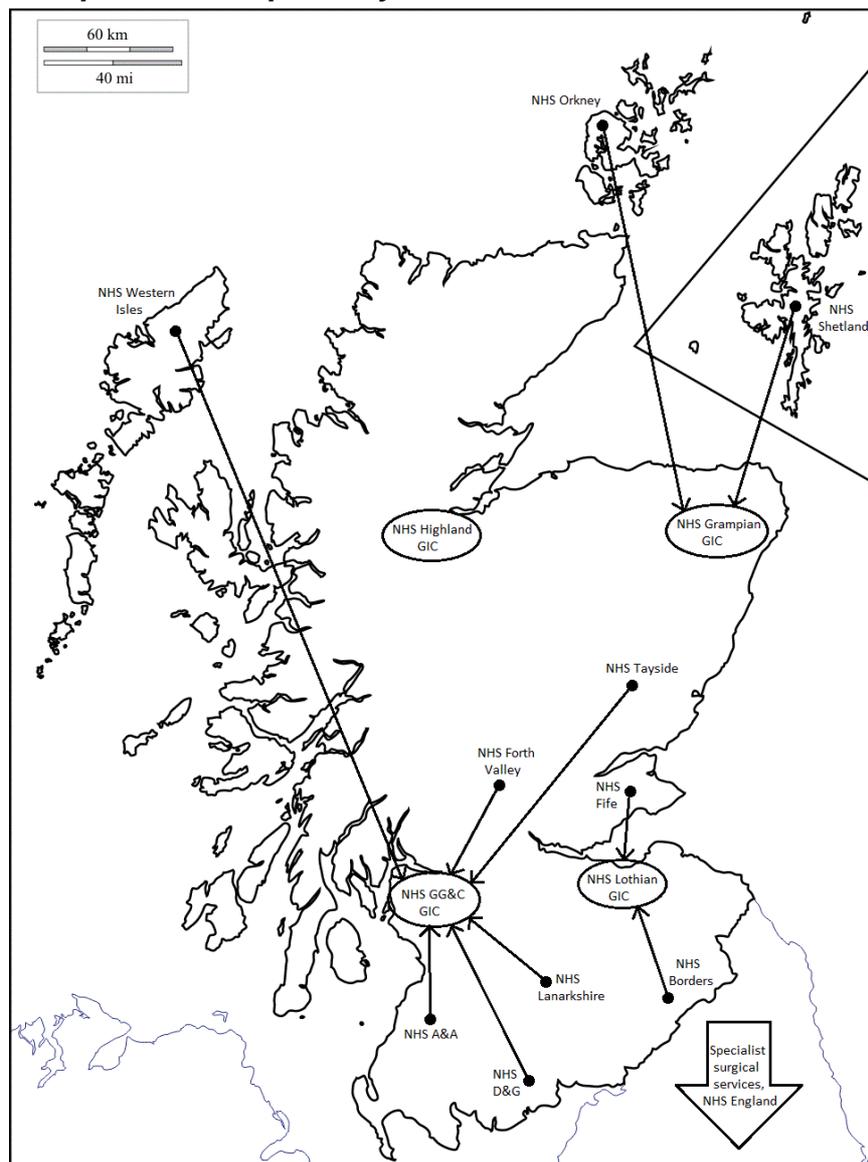
In Scotland, gender reassignment treatments that are available on the NHS are outlined in the 2012 Gender Reassignment Protocol (GRP)(13). This is based on the latest clinical standards from The World Professional Association for Transgender Health (WPATH) (1). The protocol includes a flowchart that outlines the potential patient pathway through gender reassignment treatments, including hormone treatments, surgery and a 12-month period of trans people living in their preferred gender before surgery (see Appendix). NHS boards were encouraged to provide equitable and timely services that fit with the protocol's recommendations.

Some procedures not deemed exclusive to gender reassignment, for example breast enlargement, had until recently been covered separately by the Adult Exceptional Aesthetic Referral Protocol (AEARP)(14). However, following an

audit by Health Scotland and subsequent review by the National Gender Identity Clinical Network for Scotland (NGICNS), new interim guidance was issued in March 2017 advocating revision of the GRP to remove any application of the AEARP to gender reassignment patients in order to address inequities in access to treatment(15). While this agreement is now in place in principle, specific pathways for its implementation have yet to be tested.

In Scotland, there are four gender identity clinics (GICs). The largest is the Sandyford Clinic in Glasgow, which is also the only clinic in Scotland that sees young trans people (aged under 18 years). There is also the Chalmers clinic in Edinburgh, and two smaller GICs in Aberdeen and Inverness. Health professionals working in GICs come from a variety of training backgrounds, most commonly psychiatry and sexual health. Each Scottish GIC operates differently in terms of accepted referral criteria and pathway, staffing, number of patients seen, and service provision.

**Figure 1: Map of referral pathways to Scottish GICs**



While there are no recognised GICs in other boards, some provision of less specialist services occurs locally, for example psychological support and SALT; provision of these services varies between health boards. Nationally contracted gender reassignment surgery is provided via NHS England in Manchester, London, or Brighton according to which surgery is required. Referral pathways for Scottish trans adults are illustrated in Figure 1.

Demand for both adult and young people's gender identity services have been increasing in recent years, both nationally and internationally(16)(17). There is concern about provision of and access to specialist gender identity services, with long waiting times being an issue(11)(16)(18). Almost half of trans people in the UK who want to undergo some form of medical intervention but have yet to have it cite long waiting times as the reason, and one in four don't know how to access the form of medical intervention they want(19).

Concerns around this increase in demand led to a local healthcare needs assessment (HCNA) being carried out in NHS Greater Glasgow & Clyde (GG&C) in early 2017. Following this, it was identified that a national needs assessment was likely required to fully explore the implications and inform future planning of services.

## **Aims and Objectives**

The following aims were developed for this HCNA:

- To identify the level of need and map current service provision
- To understand the service user experience and access to services
- To understand how the current gender reassignment protocol is being adhered to and what support services are important to users
- To identify the inequalities resulting from current service provision

The desired outcome was to achieve a clearer understanding of the national holistic service and how it relates to the needs of service users.

## **Structure of this HCNA**

Following this introduction is a chapter outlining the methodology, after which the document is split according to each of the three main components of a HCNA. At the end of each section there is a summary of findings alongside a 'What Does This Mean For Us?' box, outlining the key public health implications of these findings for the trans population and those planning their healthcare services. The document ends with a chapter summarising a statement of need based on the results, followed by recommendations to address these needs.

## Chapter 2: Methods

### Healthcare Needs Assessment Methodology

HCNAs aim to inform the planning of and change in health services so that positive service developments can be made and health improved(20). This HCNA is based on standard methodology and includes epidemiological, corporate, and comparative elements of needs assessment(20). The epidemiological aspect considers prevalence and availability of services; the corporate aspect incorporates views of relevant stakeholders, in this case staff working with gender identity services and those involved in related services including the third sector; and the comparative aspect makes comparisons with other services and models of care.

Literature on HCNA highlights the difference, and overlap, between needs, demand and supply(20). Needs may represent healthcare needs, from which people have the potential to benefit from interventions, or health needs, which are broader but may not reflect potential to benefit or be as helpful for planning healthcare services(20). Demand reflects expressed needs, or what people ask for(21), and can be influenced by a variety of factors including media, knowledge of services, individual illness behaviour, and supply(22). Supply indicates what health services are provided, and is affected by resources, healthcare planning, and provision(20).

The distinction between needs, demand, and supply is important as although they overlap knowing about one may not provide accurate information about another, e.g. knowing that demand has increased may not provide information on whether need has changed, especially if supply of services has also changed. This assessment originated from a question about increased demand for a particular healthcare service and the requirement for further information to inform future planning of this service, and so focused largely on demand, though underlying need is discussed.

A project steering group was brought together involving representation from the Scottish Public Health Network (ScotPHN) and relevant third sector organisations including the Scottish Trans Alliance, Stonewall Scotland, and LGBT Health and Wellbeing, due to the desire for a strong focus on the needs of service users. The original project proposal outlined the proposed broad methods of achieving the stated aims and outcome, based on the three components of HCNA described above:

- Mapping of policy, current work in area and stakeholders
- Epidemiological assessment of current and future services
- Corporate assessment of service providers and service users
- Comparative assessment of services in other countries

These were achieved using a variety of methods including a literature review, collection and analysis of quantitative and qualitative data, and secondary analysis of existing qualitative data. The decision was taken to incorporate any work which had been undertaken for NHS GG&C's HCNA into this new national HCNA, to give a more complete picture of services. The steering group met monthly throughout the process and provided feedback and comments on the planned methodology and drafts of the report.

## **Literature Review**

Knowledge Services at NHS GG&C conducted literature searches of key databases and grey literature. The searches were structured around five questions:

- What is the prevalence of gender dysphoria and transgender identities?
- Is there evidence of future trends or projections of demand for gender services?
- Is there evidence of inequalities in access to gender services, e.g. by geography?
- Are views of gender among young people changing?
- What models of care for gender services are in use?

Searches were run in February 2017 on Medline, Embase, Cinahl, PsycInfo and Google. Appropriate search terms were selected for each question and are available on request. Identified papers were screened for relevance by title and abstract. Further references were obtained from the reference lists of identified papers.

A further literature search was performed to access specific detail on international provision of gender services in January 2018. Key databases and grey literature were again consulted by a ScotPHN researcher. To further support this a range of government departments in Sweden, Norway, Finland, Iceland, Denmark, Ireland, Australia (Victoria), Thailand, Morocco, France, Germany, India and Iran were contacted for information as well as several non-governmental organisations in Australia, the US and Canada. This generated a relatively weak response, although some information was provided by Scandinavian governments.

## **Data Analysis**

### **National Surgical Data**

Data on the number of gender reassignment surgeries performed by NHS England on all Scottish residents were sought from NHS National Services Division (NSD). Figures were requested by individual health board, however due to small numbers and confidentiality concerns it was not possible to provide

this. Data were available from 2013/14 onwards and broken down by type of surgery requested. As referrals are centrally processed by NSD this will include all individuals accessing these services through the NHS within the time period.

### **Gender Identity Clinic Data**

Referral data were sought from all four Scottish GICs, but were not made available from NHS Grampian. Data from the Sandyford GIC was extracted from the National Sexual Health System (NaSH), a clinical electronic records system for sexual health clinics that holds individual level data including basic demographic information and details on referral dates(23). CHI numbers are not routinely recorded, nor are birth sex or gender identity. Clinical details, e.g. eventual treatments, were not available from this system. Data from the Lothian GIC were extracted from a separate clinical electronic records system used solely by that service, which provided comparable information to NaSH. Data from the Highland GIC were extracted manually from patient case files.

Data were available from 2014 onwards for all centres, and were anonymised. Data extraction for Highland took place in November 2017, while data extraction for Sandyford and Chalmers took place in December 2017. The fields available were:

- Date of referral
- Date of first appointment
- Waiting time to first appointment
- Source of referral
- Age at referral
- Health board of residence
- Scottish Index of Multiple Deprivation (SIMD) quintile (derived from postcode data)

Patients referred to the Sandyford were divided into young people (age at referral <17 years old) and adults (age at referral >= 17 years old). This age was chosen following discussion with the Sandyford YP service lead, as 17 year olds being referred are likely to be placed on the adult waiting list owing to the potential waiting time to an appointment. Exceptions to this rule were made in a very small number of cases (n=2) where it was explicitly recorded that 16 year olds had been referred directly to adult services.

Small amounts of data were missing for source of referral (6.4% of adults, 2.5% of young people), SIMD quintile (3.7% of adults, 1.2% of young people) and health board of residence (1.1% of adults, 1.2% of young people). There was no attempt to impute missing data for any of these variables. Data on waiting times to first appointment were not available for a majority of patients from Sandyford who had been referred in 2017 (90.2% of adults, 84.7% of young people) as they had yet to receive an appointment at the time of data extraction.

Therefore, for completeness analyses for 2017 included these individuals, though they were analysed separately in waiting time analysis.

Descriptive analyses of data were carried out to explore time trends and possible inequalities in access to services, and for adults this was done nationally and by individual GIC. More specifically, tabulations were produced for each variable, plus cross-tabulations by year of referral. Waiting times and age at referral were analysed using descriptive statistics (median and mean) and, where a linear relationship was demonstrated, tested for statistical significance using linear regression. The data were analysed in Microsoft Excel and Stata v12, with some graphs created in Tableau.

Further comparable data from other gender identity services in the UK was sought through online searches.

### **Service User Data**

The Scottish Trans Alliance (STA) were able to provide both quantitative and qualitative data from an anonymous survey of those who reported attending or being on the waiting lists for GICs across Scotland in the preceding 3 years, administered between August and November 2016 in collaboration with the Gender Identity Research and Education Society (GIREs). The survey had been administered online via Survey Monkey, with paper copies available on request, and advertised through both STA and GIREs mailing lists and social media profiles. Flyers were also distributed at various community events. Questions included quantitative elements, largely Likert scales regarding certain aspects of individuals' experience of GICs, and free-text elements allowing respondents to add comments.

Data from Scotland were originally processed and quality assured manually by a policy researcher from STA. Where applicable, Pearson's chi-squared tests were carried out to evaluate whether differences between groups were statistically significant. Secondary analysis of this data was performed, summarising key themes and incorporating non-identifiable quotes from trans people who reported attending GICs in the preceding three years. Presentation of the data was retrospectively sense-checked with the STA policy researcher who had been involved in administration of the survey.

### **Interviews with Stakeholders**

Semi-structured interviews were carried out with service providers from Scottish GICs, professionals involved in trans healthcare in Scottish NHS boards without a GIC, and individuals from specialist trans and LGBTQ+ organisations and advocacy groups in Scotland. All interviews were conducted either in person or by telephone, except for one which was conducted by email, and permission was sought from the interviewees to use their responses in an

aggregated and anonymised way. There was a mix of individual interviews and small focus groups, which ranged in size from 2-4 interviewees.

The interviews were based around a list of pre-determined questions which aimed to cover the agreed aims and objectives of the HCNA (see Box 1). For individual interviews, notes were taken during the interview and typed up immediately afterwards. For focus groups, interviews were recorded and transcribed immediately following, after which the recording was deleted. The responses were then collated according to the questions covered, and the main themes summarised.

### Box 1: Questions for Interviews

- What is the current pathway through services for people accessing gender identity services in your area? Which services are able to be provided locally?
- What proportion of patients complete the pathway or start gender reassignment treatment? Has this changed?
- Has demand for services been increasing in your area? If yes, why do you think this might be happening?
- Do longer waiting times have a detrimental impact on your patients?
- Are there any barriers or bottlenecks for patients moving along the care pathway?
- Do you think there are potential sources of inequalities in access to gender identity services in your area?
- Has the type of patients you have been seeing changed?
- What is the current approach to people moving on or being discharged from specialist gender identity services in your area?
- How often are you aware of patients using services outside the NHS to support their care, including third sector, UK private and international private provision?
- What do you expect to happen to demand in the future?
- What do you think could be done to address changes in demand?
- Are you anticipating or planning any changes in gender identity services in your area?
- Are any changes needed to the way gender identity services across Scotland work together?
- Do you collect any data on user satisfaction?
- Do you have any other comments?

## Chapter 3: Epidemiological Needs Assessment

### Literature Review

This literature review addressed the following questions:

- What is the prevalence of gender dysphoria and transgender identities?
- Is there evidence of future trends or projections of demand for gender services?
- Is there evidence of inequalities in access to gender services, e.g. by geography?
- Are views of gender among young people changing?
- What models of care for gender identity services are in use?

A relatively large number of references were found for the questions on prevalence, inequalities and models of care, whilst little evidence was found regarding future trends or views of young people. No trial evidence was identified, as would be expected from the nature of the questions asked. Whilst a number of cross-sectional survey studies and small cohort studies were identified no large observational studies of high quality were found, reflecting a lack of data on this population group. Many other articles were reviews, opinion pieces, and descriptions of models of care. It was difficult to systematically grade the quality of evidence found due to the nature of the evidence and limited number of empirical studies. Instead, the study designs are commented on where applicable.

#### **What is the prevalence of gender dysphoria and transgender identities?**

There is no commonly accepted prevalence estimate of gender dysphoria or transgender identities in the UK or internationally, as population wide data about the number of trans people is not available. Instead, a number of studies have attempted to estimate the prevalence of transgender identities using various methods and definitions of gender identity. These definitions can range from measures based on the number of people having gender reassignment surgery, to surveys that ask people about their self-reported gender identity. The methods and definitions used influence the prevalence estimates that are produced.

Table 1 shows examples of prevalence estimates from the literature and illustrates the variety of methods used and prevalence estimates made. Many older studies tend to focus on referrals for gender reassignment treatment or official change in gender and produced estimates of the prevalence of transsexualism, a narrower definition of trans identities that describes people who change their sex characteristics using medical interventions (1)(24)(25)(26)(27). More recent studies have attempted to estimate prevalence through surveys that ask people about their gender identity. For

example, Flores *et al* used the CDC's Behavioural Risk Factor Surveillance System to analyse the prevalence of US adults stating that they consider themselves to be transgender - overall 0.6% identified as transgender(28). In New Zealand, school pupils were asked about their gender identity in a health and well-being survey and 1.2% reported that they are transgender(29). A further recent study in the Netherlands on people aged 15 to 70 years old produced a potentially higher estimate, with 4.6% of natal males i.e. those assigned male at birth (AMAB) and 3.2% of natal females i.e. those assigned female at birth (AFAB) stating that they are ambivalent about their gender identity, i.e. they don't feel a strong sense of attachment to their assigned sex at birth; a smaller proportion, 1.1% of natal males and 0.8% of natal females, identified as having an incongruent gender identity, i.e. they identified more with the other sex than the sex assigned at birth; this percentage fell further, to 0.6% of natal males and 0.2% of natal females, when people were also asked about whether they disliked their body and wanted gender reassignment treatment. While it considered ambivalence towards gender identity, the study did not seek to establish prevalence of non-binary gender identities i.e. those whose identify as neither male nor female(30). These findings illustrate the variety of ways in which the prevalence of transgender identities can be measured, and the potential variation by location, age group and definition used.

In the UK, in a now slightly dated study, Wilson *et al* estimated the prevalence of gender dysphoria in Scotland by sending a questionnaire to general practitioners asking them about numbers of patients with gender dysphoria (31). This study produced a prevalence estimate of 8.18 per 100,000 in people aged over 15 years. A 2009 report by the Gender Identity Research and Education Society (GIRES) used existing evidence and surveys to make estimates of the prevalence of transgender identities in the UK(32). They stated that estimates needed to be increased and that the prevalence of people with transgender identities may be around 20 per 100,000.

Recent systematic review evidence provides further, useful estimates of prevalence. Collin *et al* used a standard systematic review method to produce an overall prevalence estimate of 9.2 per 100,000 people being transgender (33). However, they found that the different ways of measuring transgender identity, e.g. based on diagnoses, gender reassignment surgery, or applications for formal sex change, produced different estimates of prevalence, with much higher prevalence noted when estimates were based on self-reported gender identity. Arcelus *et al* also undertook a systematic review and meta-analysis of the prevalence of transsexual individuals, in this case people being referred to clinics or receiving cross sex hormones or surgery(34). They produced a lower overall prevalence estimate of 4.6 per 100,000.

**Table 1: Selected Examples of Prevalence Estimates**

Author	Country	Sample	Measure used	Prevalence estimate
Wilson <i>et al</i> (1999)	Scotland	Survey of general practitioners	Number of patients with gender dysphoria	8.18 per 100,000 over 15 year olds
De Cuypere <i>et al</i> (2007)	Belgium	Plastic surgeons and gender teams	Questionnaires about transsexual patients who had had gender reassignment surgery	Trans women 7.74 per 100,000 and trans men 2.96 per 100,000
Veale (2008)	New Zealand	Passport holders, N = 385	Number of transsexual people with an X on passport (indicating change of gender)	1:6,364 (Trans women 1:3,639 and trans men 1:22,714)
Blosnich <i>et al</i> (2013)	USA	Veterans in healthcare database	ICD-9 diagnosis codes for gender identity disorder	22.9 per 100,000 in 2011
Dhejne <i>et al</i> (2014)	Sweden	N =767	Applications for legal and surgical sex reassignment	Point prevalence in 2010 1:7,750 trans women and 1:13,120 trans men
Kuyper and Wijzen (2014)	Netherlands	N = 8,064 15-70 years old	Self-reported gender identity and dysphoria	1.1% natal* men and 0.8% natal* women reported incongruent gender identity
Clark <i>et al</i> (2014)	New Zealand	N= 8,166 school students in a nationally representative survey	Self-reported gender identity (“Do you think you are transgender?”)	1.2% transgender and 2.5% not sure about their gender in 2012
Crissman <i>et al</i> (2017)	USA	N= 151,456 adults	2014 Behavioural Risk Factor Surveillance System (telephone health survey); self-reported gender identity	0.53% (95% CI 0.46, 0.61)

\* natal men and natal women refers to people born male or female, respectively

Prevalence of transgender identities may also vary between population subgroups. The most evident variation in the literature is the difference in prevalence between those AMAB and those AFAB. Generally, higher prevalence is noted in natal males(35)(36)(37). However, this difference may be decreasing, especially among younger people(38)(39)(40). Prevalence has also been noted to vary geographically. For example, the prevalence of people presenting for gender reassignment surgery in Belgium was found to vary regionally, with lower prevalence noted in an area in which being trans may have been less socially acceptable(36).

Estimating the prevalence of transgender identities is difficult for a number of reasons. There is no standard approach for asking people about their gender identity, there is a lack of routine data, and, as discussed above, there are various ways of measuring transgender identities(41). Other challenges to measuring trans identities on a routine basis include privacy, the acceptability of questions, legality (as data should not allow a person to be identified as being trans), and the complexity of definitions and terminology used(42). A further challenge is that gender identity may change and is very individual(43).

It is likely that many estimates of the prevalence of transgender identities are underestimates, especially those based on numbers seeking healthcare(44). Indeed, evidence from a 2013 European survey of LGBT people suggests that a high proportion of trans people have not sought medical help (34% in the UK), with many of these feeling they do not need it (56%)(45). A more recent 2017 UK survey by the LGBT charity Stonewall found that only 52% of trans people in the UK have undergone or are currently undergoing medical intervention, but that almost one in four (23%) want some form of medical intervention that they have not yet been able to access (19). There can be stigma associated with seeking healthcare meaning that some trans people may not present, perhaps because of fear of prejudice from healthcare providers (45)(46). Therefore, there are likely to be more trans people in the population than many studies based on use of health services suggest. However, many of those who have not sought or been able to access medical intervention will still turn to the third sector or peer support groups for information and support for their broader trans-related health needs, and demand for these services may be more representative of prevalence.

### **Is there evidence of future trends or projections in demand for gender services?**

There is consistent evidence that demand for gender identity services has been increasing in recent years. Media reports have highlighted these increases(17)(47), which appear to have happened among both adults and young people. For example, Wood *et al* note that the number of young people referred to a gender identity service in Canada has increased markedly since 2004(48); referrals to young people's gender identity services in England have also notably increased(17)(49). Dhejne *et al* found that the incidence of applications for gender reassignment surgery in Sweden increased between the 1970s and 2000s(49). Additionally a European online survey

found that the trans population appears to be increasing every year, with many of the trans respondents reporting that they had transitioned recently(50).

Authors have offered a range of explanations for the increase in demand. These include:

- Increased awareness, visibility and tolerance of trans people(17)(51)
- Increased media coverage and the availability of social media and the Internet (48)(50)
- Better availability of healthcare(48)
- Greater legal protections(51)
- Increased peer support, social status and empowerment(48)(50)(52)
- A true increase in prevalence(48), with environmental factors affecting pre-natal gender identity development being an issue(32).

It is unclear whether the increase in demand coincides with an increase in prevalence of people with trans identities. Survey evidence from the US suggests that more recent estimates of the prevalence of trans identities may be higher, although methodological differences could account for some of this increase(28). Further it may be that people are more willing to identify as being a trans person. Increases in demand for health services cannot be assumed to represent an increase in prevalence as they may also stem from trans people being more willing to come forward for healthcare or increased service availability(48)(53).

These increases in demand have implications for service provision and planning (32)(50). However, no studies were found in which formal projections of future prevalence or demand have been made. Instead, there is general opinion that health service provision needs to increase(54), that more people may present making a greater variety of requests for gender reassignment treatments than have done previously(55), and that we need to find out more about people who are not accessing care(46). A notable consideration given the increase in young people presenting to gender identity clinics is the likely persistence of gender dysphoria into adulthood, a factor which will have implications for adult service provision – it is estimated that up to 27% of pre-pubescent children presenting will have symptoms that persist into adulthood, with a higher proportion of adolescents having persistent symptoms(56).

With no formal projections of prevalence or demand found, there is little to no evidence that can be derived from the literature to inform health service planning in terms of the length of time that increases in prevalence could be expected to continue for. Therefore, changes in clinical activity and the perspectives of trans people are likely to provide the best evidence for this. In 2009 and 2011, GIRES stated that increases in incidence might carry on for a long time, and suggest that service providers plan for similar growth rates to continue for a “lengthy period”(32)(52).

## Is there evidence of inequalities in access to gender services, e.g. by geography?

Considering inequalities from a broad and global perspective, it has been highlighted that trans people experience health inequalities related to poorer social and economic circumstances, stigma and discrimination, violence, and difficulties accessing healthcare and other services(5)(57). Indeed, the ability to affirm one's own gender has been described as an important social determinant of health(49). A rights-based approach to transgender health has been advocated(57). Evidence from the US suggests that there are socioeconomic differences between trans people and the rest of the population. For example, Crissman *et al* analysed survey data and found that trans people were more likely to be nonwhite, below the poverty line and less likely to have attended college(35). Similarly, Conron *et al* found that transgender people were more likely to be Hispanic, unemployed and in poverty(58). Whilst this evidence suggests the presence of socioeconomic inequalities these findings may not be entirely generalisable to the UK.

One part of these broader determinants of health and potential causes of health inequalities is that trans people may have difficulties accessing healthcare(57). Barriers to accessing healthcare have been documented in a number of settings and relate to a number of factors including stigma and discrimination, and limited availability of appropriate services. For example, White Hughto *et al* write that stigma is a common experience for trans people and may lead to poor health outcomes through stress and reduced access to healthcare(59). Further, participatory research evidence from the US indicates that transgender people experience discrimination in healthcare and difficulty accessing services(60). A qualitative interview study from Sweden found that trans people found healthcare difficult to navigate with long waiting times and a lack of support; interviewees highlighted that access to care seemed to depend on a person's ability to take control of their own care (61). In the US, Gridley *et al* found that young people and their carers experience a number of barriers in accessing healthcare, including a lack of healthcare providers, inconsistent use of care protocols and incorrect use of names and pronouns(62). It may be that some difficulties arise because of healthcare providers' views of trans people. Indeed, qualitative interviews with sexual health providers in England identified a potential lack of understanding of trans issues, with providers seeing trans people as being mentally unwell and seeing gender identity as a binary concept(63).

This evidence is likely to be most relevant to the healthcare settings in which it was conducted. However, there is further evidence from the UK of trans people experiencing difficulties in accessing healthcare. The UK Equality and Human Rights Commission has identified a number of barriers for trans people accessing services in England including lack of GP support or slow referrals from primary care, geographical variations in policies and funding for treatments, complexity of the care system, long waiting lists, a lack of choice and a view that clinics take too narrow and restrictive an approach to providing treatments(64). Concerns about the Scottish gender

reassignment protocol have been raised, including difficulties in its implementation (particularly in achieving access to counselling), long waiting times, lack of flexibility in care pathways, lack of inclusion of diverse needs (such as those of non-binary individuals), restricted access to surgery, geographical variation in treatment provision, and challenges of rural access(65).

### **Are views of gender among young people changing?**

A question that was raised in the development of this assessment was whether views of young people around gender are changing. A limited amount of evidence was identified on this issue, perhaps because changes may be very recent. Some of the potential explanations for the increase in demand for gender identity services described above may also apply to this question, e.g. societal change may mean young people feel more able to talk about their gender identity.

Media reports suggest that more young people are not conforming to gender stereotypes and that generation Y is the “gender fluid generation”(66). A gender specialist working with young people in England comments that there has been a societal and cultural shift in conversation about gender, with greater acceptance of transgender people and a move away from seeing gender as a binary concept(67). In a commentary article, Pyne suggests that there has been a change in how gender nonconforming children are viewed by other people(68). This is described as a positive change from being transgender being seen as a disease, to being an issue of diversity requiring affirmation, pride, and community rather than treatment and cure. However, there is also evidence from young people of negative experiences of being trans, with media stereotyping an issue and young people fearing the reactions of friends and family to their trans identity(69)(70). A recent unpublished survey by LGBT Youth Scotland found that a high proportion of trans young people experienced transphobia and bullying, whilst only 48% of trans young people felt safe and supported by the NHS in relation to their gender identity(71)(72).

### **What models of care for gender identity services are in use?**

There is a degree of consensus in the literature about the general healthcare needs of transgender patients(5). Worldwide, frequently repeated ideas for improvement include gender affirming communication, education of health professionals(73), implementation of principles of best practice(74), cultural competency(75), and shared-decision making(76). Stonewall have made suggestions for health and social care above and beyond these based on extensive consultation with trans communities across the UK about their experiences, insisting on the need for greater financial resources, incentives for gender specialists, and new models of care which are not restricted to the current clinical model in which treatment requires a psychiatric diagnosis(77).

The literature demonstrates the availability of guidelines on transgender care and various models of care that are currently being used in different settings.

## **Guidelines**

The principal guideline identified was by the World Professional Association for Transgender Health (WPATH), which publishes standards of care for the health of transgender people(1). This guideline outlines clinical care and interventions to be offered to transgender people, including providing criteria for hormone treatment and surgery, and outlining the role and competencies for mental health professionals. The most recent version of this guidance (WPATH7) advocates a flexible approach to care and states that gender nonconformity should not be seen as a pathological process, and was the first set of standards to explicitly state there should be access for non-binary individuals. However, as yet there is no international guidance on how to diagnose non-binary people with gender dysphoria, or indeed how to assess people for the new diagnosis of gender dysphoria rather than the old diagnosis of transsexualism.

A contrast to the WPATH approach is outlined by Cavanaugh *et al*, who support the use of an informed consent model of care where transgender people have the right to choose their own treatments without needing input from a mental health professional (78). They state that the WPATH guidelines are not flexible enough and rely upon mental health assessments, whereas the informed consent model could provide better care through taking a collaborative approach where a mental health professional does not make decisions about treatment. A variety of other guidelines on providing healthcare for trans people were identified(79)(80)(81).

In a useful review of transgender healthcare, Wylie *et al* advocate the use of the WPATH guidelines (although it is noted that the number of the authors are on WPATH) (12). In this review they highlight that most healthcare for trans people can be provided in primary care. Further, they outline three important themes in the literature on models of care for transgender people - the leadership role of the trans community, need for multidisciplinary services, and use of partnerships. In Scotland, the 2012 gender reassignment protocol provides the main source of guidance on interventions for changing gender and is based on the WPATH approach(13).

## **Examples of Models of Care from Elsewhere**

A variety of models of care were identified in the literature, mostly from North America. Many use the WPATH guidelines and tend to be based on flexible and multidisciplinary approaches to providing care.

Examples include a multidisciplinary mental health and medical service for young trans people in Boston that is reported to provide flexible and individual care for its patients (82). Interestingly, it is commented that the amount of demand for the service was not recognised before it opened, and that they had a large number of enquiries when the service began – an example of potential unmet need or of supply influencing demand. Also in Boston is a community clinic called Fenway health(83). This clinic provides healthcare for lesbian, gay and bisexual people as well as trans people. Their approach to trans healthcare involves using a modified version of the informed consent

model; the care is described as being accessible, multidisciplinary, gender affirming, and holistic, with gender affirmation seen as a part of normal primary care and not as a mental health problem. This clinic also provides a wide range of other health services for trans people, including complementary medicine, dentistry and primary care. It is also reported that this clinic has seen increases in patient numbers and has relocated to bigger premises. Other services were identified in the US and Spain with models of care based around the WPATH guidelines(84)(85).

Another interesting example of a model of care comes from British Columbia(86)(87). Here the service provider, Trans Care BC, works with trans people, their friends and families, and healthcare professionals to support the local provision of healthcare for trans people. Indeed, a core aim of this service is to enable trans people to get most of their healthcare from their primary care provider. The service aims to achieve this using a range of approaches, including the provision of clinical advice, information, mentorship, and education for healthcare professionals. Further, the service provides help for patients to navigate the health system, co-ordination of surgical readiness assessments, and promotion of best practice in the care of trans people. Video technology is used in their work. They state that they take a gender affirming and patient centred approach in their model of care.

In England the development of transgender health services is underway, and services are being asked to develop and make plans for dealing with increased demand (18)(88). In a recent symposium, participants advocated that a more multidisciplinary and less psychiatric approach is adopted in specialist transgender health services, which should also be person centred and use shared decision-making(89).

A range of studies and reports also indicate the important health impact of getting models of care right for trans people. These include reports that long waiting times for appointments can worsen mental health and well-being(90), and that when people are eventually seen at gender clinics many are already taking hormones accessed elsewhere, for example from the Internet(91). Furthermore, it has been highlighted that discrimination in health services can negatively impact on health(92), and that having a transgender inclusive healthcare provider may be associated with improved mental health(93). These reports advocate for individualised and flexible approaches to care that are not overly medicalised(50)(90)(92).

Further exploration of treatment models in the rest of the UK and internationally is presented in Chapter Five, containing a full comparative assessment of services.

## **Summary**

This literature review addressed five key questions on the prevalence of transgender identities, future trends in demand, inequalities in access to services, views of young people about gender, and models of care for gender services. A number of studies on the prevalence of trans identities were found but no accurate estimate of prevalence was available. Further, whilst there is consistent reporting of increases in demand for

services no attempts at making future projections of these increases were found. There is evidence of inequalities in access to healthcare for trans people, including in the UK. However, evidence on changing views on gender among young people was limited. Finally, a range of models of care for gender identity services were found, many of them based on the principles of flexible, multidisciplinary and person-centred care with some providing this in specialised clinics and others in primary care.

## What Does This Mean For Us?

We know that NHS and third sector services for transgender people in Scotland have noticed an increase in demand over several years that they are finding challenging to manage. There are no firm estimates of the number of trans people living in Scotland, or predictions of how the number of trans people seeking medical help with their transition may change in future, which makes planning services difficult. It's likely that, without this evidence, using changes in referral numbers to Scottish services over time and speaking to those who deliver services and use them may be the best possible way to predict what might happen in future.

However, we know that this will be an under-estimate of the true trans population in Scotland, because around 1 in 5 trans people do not feel they need medical help from the NHS. These people might still want and need access to other services, like third sector and peer support groups, for their broader trans-related health needs.

Trans people throughout the world report difficulty in accessing healthcare services for many reasons, including long waiting times and fear of stigma and discrimination, and it is important to know whether these are current issues for trans people accessing services in Scotland. There are not many studies which have looked at whether gender fluidity and views on gender are changing among the trans population and/or the young, but if this change is recent then better and more up-to-date information might be available from those working closely with trans communities in Scotland.

## Organisation of Services in Scotland

### Gender Reassignment Protocol

The NHS Scotland Gender Reassignment Protocol (GRP) recommends that patients may self-refer to a GIC or be referred via a GP, following which a first assessment should take place. If there is no provisional diagnosis of gender dysphoria<sup>1</sup> the patient should be discharged or referred onwards for further support.

Where the diagnosis is uncertain, ongoing support and assessment will be provided. If there is a provisional diagnosis and individuals wish to undergo genital surgery, a

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<sup>1</sup> Original wording of the Gender Reassignment Protocol states 'transsexualism/gender dysphoria', however this is no longer a commonly used term in the UK

pre-operative 12 month experience of living in the identity-congruent gender role will follow alongside a continued treatment plan and sessions offered to family members, partners, and carers of the patient. Patients are required to provide their clinic with verification that real life experience in the preferred gender has been fulfilled prior to referral for genital surgery e.g. via collateral interviews, official documentation from employers and educational institutions.

Treatments that require only one clinical assessment opinion for referral should be provided prior to, and concurrently with, the preoperative experience. This includes, for male to female (MtF) patients:

- Hormone therapy
- Facial hair removal
- Speech therapy
- Psychotherapy.

For those seeking to transition from female to male (FtM), treatments at this stage may include:

- Hormone therapy
- Speech therapy
- Mastectomy with FtM chest reconstruction
- Psychotherapy.

Following the 12 month period of real life experience a second assessment should be provided and further treatments agreed. Assessment, diagnosis, and confirmation of gender dysphoria (for both the first and second assessment) should be made by a specialist mental health professional with general clinical competence in diagnosis and treatment of mental or emotional disorders, such as a psychiatrist and psychologist. It should then be determined if patients can be referred for complex surgical intervention. As discussed in the Introduction, the documented exclusion of some such surgeries from the GRP to the separate *Adult Exceptional Aesthetic Referral Protocol (AEARP)* is no longer considered appropriate by the National Gender Identity Clinical Network for Scotland (NGICNS)(15).

If no further surgical treatments are required, patients may at this point be discharged to an appropriate clinician (with GPs made aware of the hormone management guidelines) for ongoing hormone therapy treatment. Criteria for the prescription of hormone therapies include:

- Persistent, well-documented gender dysphoria
- Capacity to make a fully informed decision and to consent for treatment
- Aged at least 16
- If significant medical or mental health concerns are present, they must be reasonably well controlled.

For genital surgeries, patients should be referred following 12 continuous months of hormone therapy appropriate to the patient's gender goals and completion of the preoperative 12 month real life experience, with two separate assessments and diagnoses of gender dysphoria from appropriately qualified professionals. Following gender reassignment surgery, a follow up appointment with the GIC should take place within 6 months, with any further treatments identified. Patients will then be discharged to GP care.

The current version of the GRP does not offer a defined pathway for those with a non-binary gender identity, or use non-binary inclusive language. Non-binary people who wish to access feminising or masculinising treatments at present require to do so via the 'FtM' or 'MtF' arms of the pathway.

### **Adult Gender Identity Clinics in Scotland**

Scotland has recognised GICs for adults aged 17 and above in four of the fourteen regional NHS boards: NHS Greater Glasgow & Clyde (Sandyford Clinic), NHS Lothian (Chalmers Clinic), NHS Highland, and NHS Grampian. All four GICs aim to adhere to the Scottish GRP and therefore the international WPATH clinical standards.

The Sandyford GIC is based within the wider Sandyford sexual health service and accepts self-referrals from individuals as well as referrals from General Practitioners (GPs), other healthcare professionals including those in mental and sexual health services, and other professionals such as third sector partners. It is currently staffed by three consultant psychiatrists, one consultant physician, one specialty doctor, one consultant psychologist, one specialist occupational therapist, and one counsellor. The service is open to individuals from any health board in Scotland, though if deemed more appropriate they will occasionally divert referrals to another more local adult GIC. Where they provide initial or ongoing assessment for individuals outwith NHS GG&C their home boards are charged via a Cross-Boundary Agreement. Second opinions for hormone treatment or surgery for Sandyford patients are usually performed within their own service.

The GIC at the Chalmers sexual health clinic in Lothian accepts referrals from health or other professionals only, and does not accept self-referrals. It has previously been permanently staffed by one consultant psychiatrist, one specialist nurse practitioner with a background in mental health, and an administrator. Currently due a planned absence it is led by the specialist nurse practitioner with the support of a robust multi-disciplinary team for review of cases, including a qualified mental health professional specialising in gender dysphoria and a medically qualified clinician or consultant. At present there is also regular support from a consultant endocrinologist and SALT, and the service has recently recruited an additional nurse specialist to increase capacity. The service accepts referrals from individuals residing in NHS Lothian, NHS Borders, and NHS Fife. Second opinions for hormone treatments take the form of a multi-disciplinary team discussion; second opinions for surgeries which require this are performed by the Sandyford GIC.

The NHS Highland GIC accepts self-referrals from individuals and referrals from health and other professionals. It runs once a month for new patients as part of the sexual health service with return patients seen approximately three-monthly and is staffed by one consultant physician who will leave the service in 2018, however they will be succeeded by another physician in this role. They accept referrals for individuals residing in NHS Highland, though some individuals from other boards in northern Scotland (NHS Western Isles, NHS Shetland) who self-refer to the service are also seen there. Second opinions for any treatment including hormone prescription are usually performed by the Sandyford GIC.

The NHS Grampian GIC was previously staffed on a locum basis by a consultant psychiatrist who is now undertaking a planned absence from the service and an administrator who has also left the service. There is currently a plan to develop the service more sustainably within mental health services, with a consultant psychiatrist, clinical psychologist, and new administrator joining the GIC in early 2018. This development is at an early stage, but the planned endpoint is a GIC able to provide initial assessment and treatment, as well as both first and second opinions for hormone treatment. Second opinions for surgery would be performed by the Sandyford GIC. The Grampian service previously accepted referrals from individuals residing in NHS Grampian, NHS Orkney, and NHS Shetland, and it is anticipated that this will continue in its new format.

### **Gender Reassignment Surgery**

There is no current provision of gender reassignment surgery in Scotland. All referrals for nationally contracted surgery are processed by the NHS National Services Division (NSD) and, if accepted, are actioned by surgical services in NHS England. Referrals for genital surgery require a second opinion assessment by a mental health professional specialising in gender dysphoria as per the GRP, and at present these assessments are provided for all individuals in Scotland by clinicians at the Sandyford GIC.

### **Children and Young People**

In addition to the above services for adults there is a national Young Person's Gender Service for individuals aged less than 18 years, based at the Sandyford clinic in Glasgow. The team is multidisciplinary, and currently includes Psychiatrists, Clinical Psychologists, an Occupational Therapist, and a Counsellor. The focus of the Young Person's (YP) Service is to support young people (and their families) experiencing gender dysphoria who are either entering puberty or are progressing with puberty. The Service has less of a role with pre-pubertal children who are supported by more local resources; this may include input from local Child and Adolescent Mental Health Services (CAMHS) and the involvement of Third Sector agencies. However, the Service offers informal consultation, support and advice to professionals working with pre-pubertal children with gender variant behaviour, and as a result is often aware of these children prior to them being referred for input after entering puberty.

When young people approach the age of 18, the Service liaises with the young person's relevant local adult GIC to ensure a seamless transfer and continuity of care.

As a result of increasing waiting times in excess of 12 months for the YP Gender Service, currently when a young person aged 17 is referred they are automatically added to the waiting list of their local adult GIC.

### **Local/Regional Provision of Gender Services**

In health boards without a formal GIC, availability and provision of local gender identity services while individuals wait to be seen and following GIC assessment is extremely variable. At present, provision ranges from a formalised 'hub and spokes' model in NHS Tayside where the local Community Mental Health Team (CMHT) can initiate specialised psychological support, SALT, and hair removal while individuals are on the waiting list for the Sandyford GIC, to smaller health boards where there is no provision of such services locally.

### **Third Sector Services**

There are a wide variety of third sector support initiatives for trans people across Scotland, including one-to-one support, helplines, counselling, groups, and social support, as well as peer-support groups. These services tend to be located in urban centres (with some exceptions e.g. Shetland LGBT) and particularly in the central belt, and what is provided varies according to the set-up and those responsible for running them. Key third sector bodies involved in delivery of such services in Scotland include LGBT Youth and LGBT Health and Wellbeing, with the latter providing formal counselling services for trans people in Edinburgh and Glasgow. An up to date list of support groups can be found on the Scottish Trans Alliance website(94).

## **Service Usage Data**

### **National Data – Adult Gender Identity Clinics**

The following section combines referral and appointment data from three of the four Scottish GICs between January 2014 and November (Highland) or December (Sandyford, Chalmers) 2017. Data from 2014 to 2016 are directly comparable for all clinics, and include only individuals who were referred and subsequently received appointments i.e. not those for whom referrals were not accepted. For 2017, Sandyford were able to provide additional data for individuals who had been referred but were yet to be appointed. This allowed a more complete picture of referral numbers in this year, as a large proportion of 2017 referrals to Sandyford had yet to be appointed at the time of data extraction. The same information was unavailable for either Chalmers or Highland GIC, however at the time of data collection both clinics had appointed all referrals received up to the end of November 2017, therefore there are likely only a small number of pending 2017 referrals to these services not included. Of note, it was decided not to attempt to stratify analysis by gender identity, partly due to small numbers, and partly due to difficulties in definitively determining this when data were documented at point of referral, which was felt to carry a risk of misgendering/misclassifying individuals in analysis.

## Limitations of Data

There are important limitations which should be considered in interpreting these data. Though the data run over four years, this is still a relatively small time frame from which to make projections of future trend directions, so these should be interpreted with caution. As the 2017 data from the Sandyford service include all individuals referred, this is likely to be a higher number than would be represented in previous years as it will include referrals the service will reject. However, this was felt to be more acceptable than the alternative of not including these individuals, therefore providing an estimate of referral numbers that was artificially much lower than the reality. In order to overcome this, in presenting the data it is clearly indicated at all points what proportion of individuals are those still awaiting review of their referral. For reference, in previous years the percentage of total referrals to the Sandyford adult service where an appointment was not offered were 16.3% (2014), 24.4% (2015), and 28.6% (2016) – this may be because the referral itself was inappropriate or another service (including another Scottish GIC) was more appropriate for the individual. It was possible to omit rejected referrals from January 2017, as these had all been reviewed at time of data extraction.

As GICs in Scotland often provide second opinions for other Scottish GICs (particularly the Sandyford service) there is likely to be a small amount of double counting of individuals, which was unable to be accounted for as for confidentiality and data protection reasons data were provided without unique identifiers. These referrals were coded as 'Internal' and again the proportion of referrals in this group is clearly discussed for transparency. It is also noted that each GIC uses different recording systems which are designed as administrative tools rather than to record data for analysis, therefore there remains the possibility that data entry error may have occurred, despite efforts by the researchers to manually clean the datasets. However, we are confident that the approach taken to data handling has minimised these limitations as far as possible, and that the data presented provide the best possible way to make judgements on trends in demand.

## Results

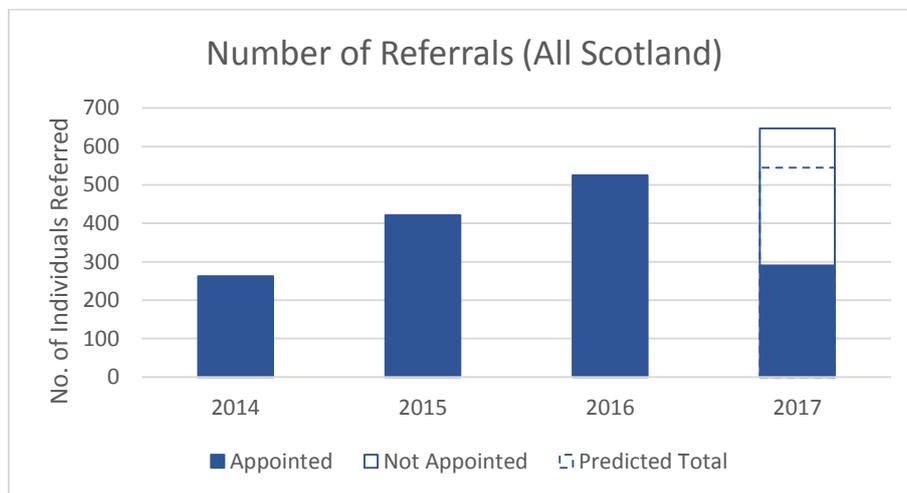
Table 2 shows the number of referrals to the three Scottish GICs in each included year, alongside the annual percentage change in referral numbers. For 2017, the total number of pending Sandyford referrals are shown alongside the predicted number of likely accepted referrals (based on 2016 acceptance rate of 71.4%), with percentage total change displayed for both figures.

**Table 2: Number of Referrals and % Change (All Scotland)**

Year	Appointed Referrals	Pending Referrals	% Change
2014	262		
2015	421		+60.7%
2016	525		+24.7%
2017	290	357 (71.4% = 255) Total: <u>647</u> ( <u>545</u> )	+23.2% (+3.8%)

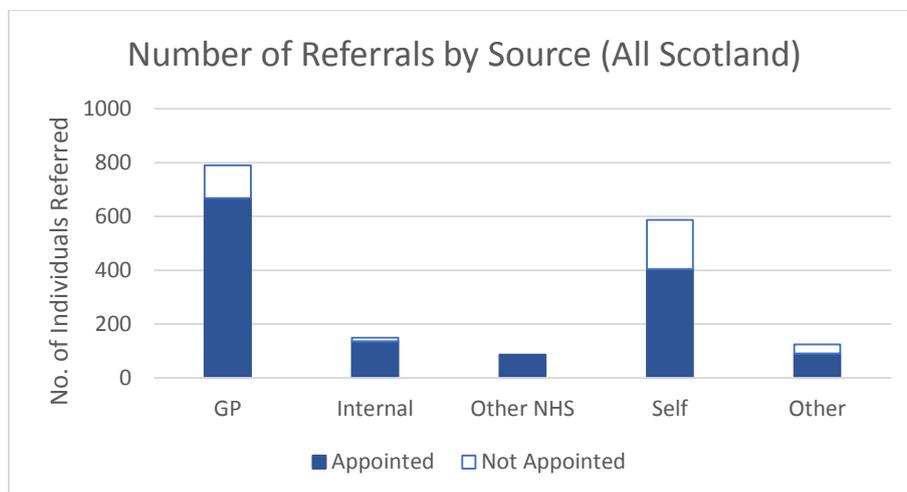
There has been an increase in referrals in all years, however the rate of increases appears to be slowing. Assuming there is no significant change in the acceptance rate for referrals to the Sandyford service, it is likely that the number of appointed referrals in 2017 will be similar to 2016 (545 vs 525). These figures are also illustrated in Graph 1.

**Graph 1: Number of Referrals (All Scotland)**



Of all referrals received by adult GICs in 2017, 55.2% have yet to be appointed. Graph 2 shows the source of all referrals to adult GICs across the four year period.

**Graph 2: Source of Referrals (All Scotland)**

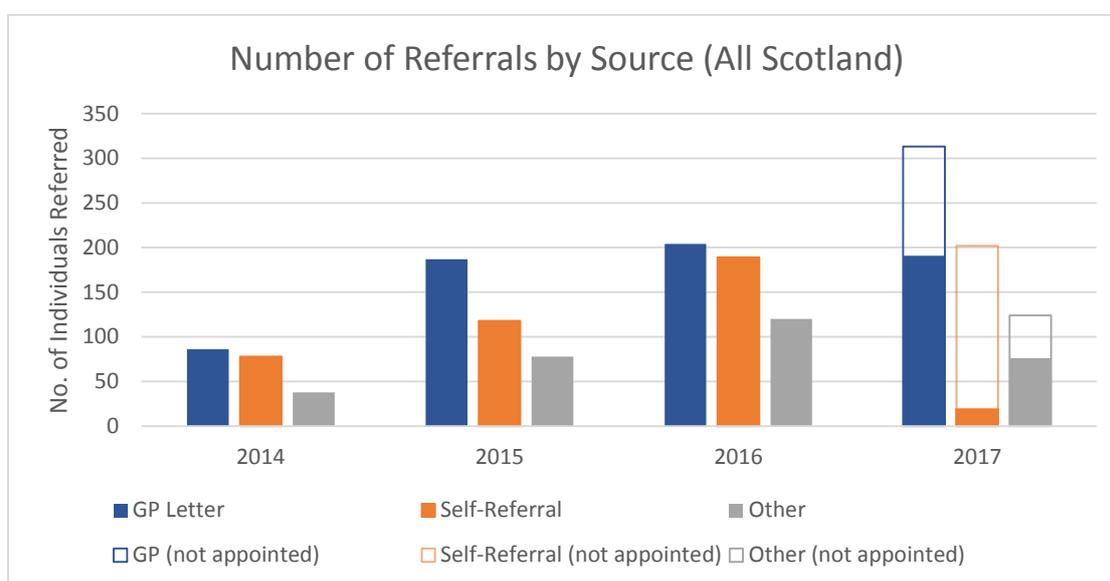


Most referrals to adult GICs throughout the study period were via a General Practitioner (45.5%) or self-referral (33.8%). Of the remaining referrals, 8.6% were coded as 'internal' (from one GIC to another), 5.0% were from other NHS services, and 8.7% were from other sources, including private medical services. These data were also broken down by year, with the resultant trends over time displayed in Table 3 and Graph 3. For 2017, again the distinction between those who have been appointed and those yet to be appointed by the Sandyford GIC is shown, alongside the predicted number of accepted referrals (based on the 2016 referral acceptance rate of 71.4%).

**Table 3: Source of Referrals Over Time (All Scotland)**

Year	GP Letter	Self-Referral	Other
2014	86	78	38
2015	187	118	78
2016	204	189	120
2017			
<i>Appointed</i>	191	19	76
<i>Not Appointed</i>	122 (total <u>313</u> )	183 (total <u>202</u> )	48 (total <u>124</u> )
<i>Predicted (71.4%)</i>	87 (total <u>278</u> )	131 (total <u>150</u> )	34 (total <u>110</u> )

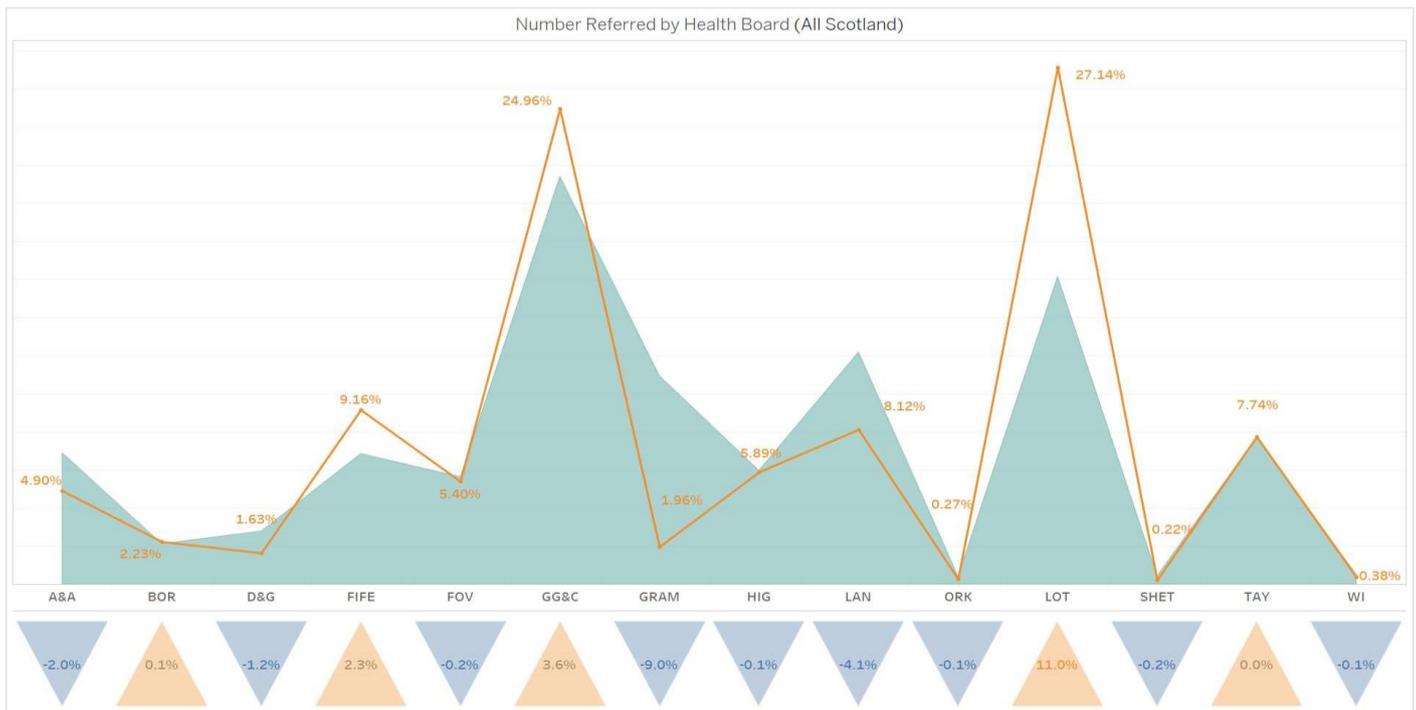
**Graph 3: Source of Referrals Over Time (All Scotland)**



There is a consistent increase in number of referrals in all categories between 2014 and 2017, with no clear trend of change in the distribution between referral sources. If the Sandyford referral acceptance rate were to remain the same it is predicted that there would be further increase in the number of appointed referrals from General Practitioners, from 204 in 2016 to 278 in 2017, while there would be a decrease in appointed referrals from the other two sources (for self-referrals 189 in 2016 to 131 in 2017; for other sources 120 in 2016 to 110 in 2017). However, the crude application of total acceptance rate to these groupings while helpful will not be as predictive as it is for the whole group, as it is likely acceptance may vary according to the source of referrals. Therefore, these predicted values should be interpreted with caution.

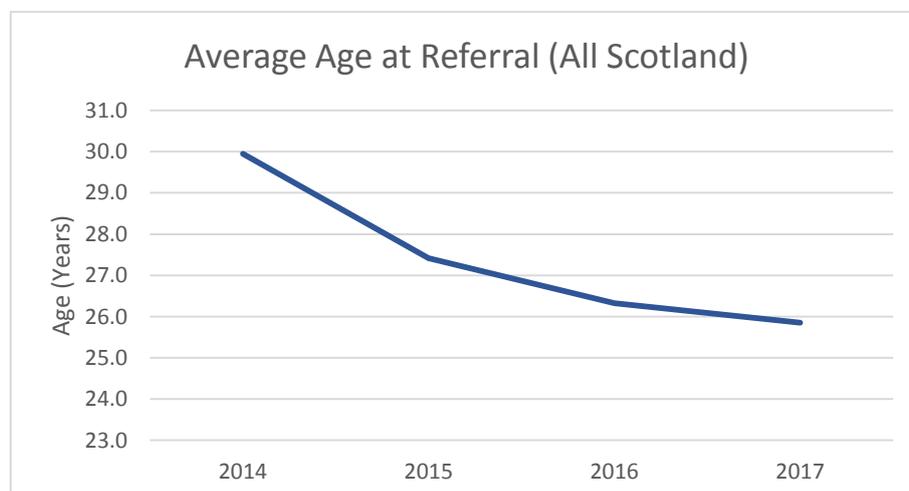
Graph 4 displays the health board of origin for all referrals (trend line), alongside the relative distribution of the national population between health boards (solid area). It is acknowledged that the absence of data from Grampian GIC will inevitably have resulted in an under-representation of referrals from NHS Grampian, and possibly to a lesser extent NHS Orkney and NHS Shetland.

**Graph 4: Number of Referrals by Health Board (All Scotland)**



There is shown to be an over-representation of referrals from three health boards based on the national distribution of the population: NHS Fife (2.3% higher than expected), NHS GG&C (3.6% higher), and NHS Lothian (11.0%), all largely urban boards. There is a marked under-representation of NHS Ayrshire & Arran (2.0%), NHS Dumfries & Galloway (1.2%), and NHS Lanarkshire (4.1%), all more rural boards. These differences from the population distribution are likely to be somewhat explained by the fact that LGBTQ+ individuals often move from rural areas to urban centres, where perceived cultural acceptance is higher (95). However, the larger over-representation for NHS Lothian is less likely to be entirely explained by this given the degree to which it differs from the other urban boards. There is also, due to lack of data, a 9.0% under-representation from NHS Grampian. Graph 5 displays the average age of young people at the point where they are referred to services.

**Graph 5: Average Age at Referral (All Scotland)**



The average age at referral to the adult GICs has fallen over time, from 29.9 years in 2014 to 25.8 years in 2017, and was shown to be statistically significant (reduction by 1.3 years of age/year, 95% CI 0.8-1.8 years,  $p < 0.001$ ). The mean age at referral throughout the whole period was 26.9 years (median 22 years, range 13-93 years).

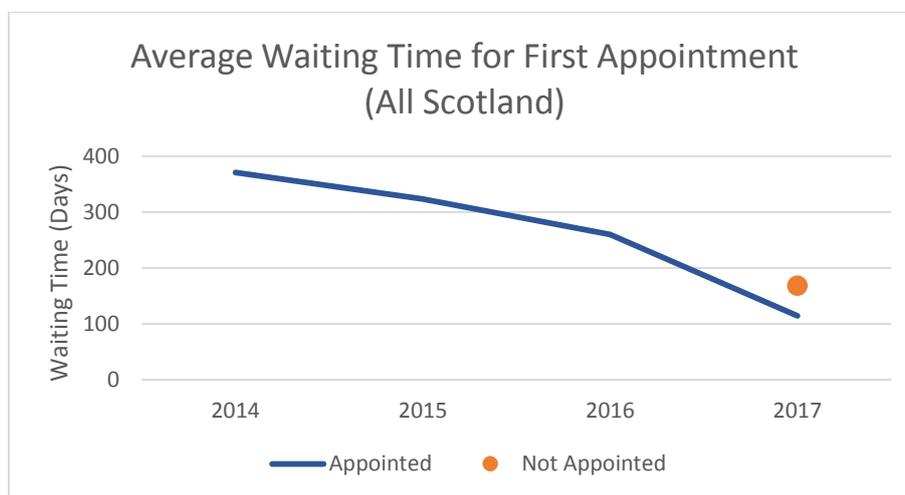
Waiting times were calculated by subtracting the date of referral from the date of first appointment, with individuals being grouped according to the year in which they were referred. Table 4 displays the mean, median, minimum and maximum number of days individuals had to wait until their first appointment at an adult GIC in each year, along with the annual percentage change in mean waiting time. For 2017 the values given are for those who had already received appointments.

**Table 4: Waiting Times by Year of Referral (All Scotland)**

Year	Mean WT	% Change	Median WT	Min. WT	Max. WT
2014	371		356	0	943
2015	323	-12.78%	361	0	575
2016	260	-19.59%	320	0	555
2017	114	-56.05%	92	0	407
Whole Period	<b>269</b>	-	<b>321</b>	<b>0</b>	<b>943</b>

For those referred in 2017 who have not yet received appointments, the mean waiting time as of 31<sup>st</sup> December 2017 was 168.4 days (median 179 days, range 2-341 days). The change in average (mean) waiting time is displayed in Graph 6.

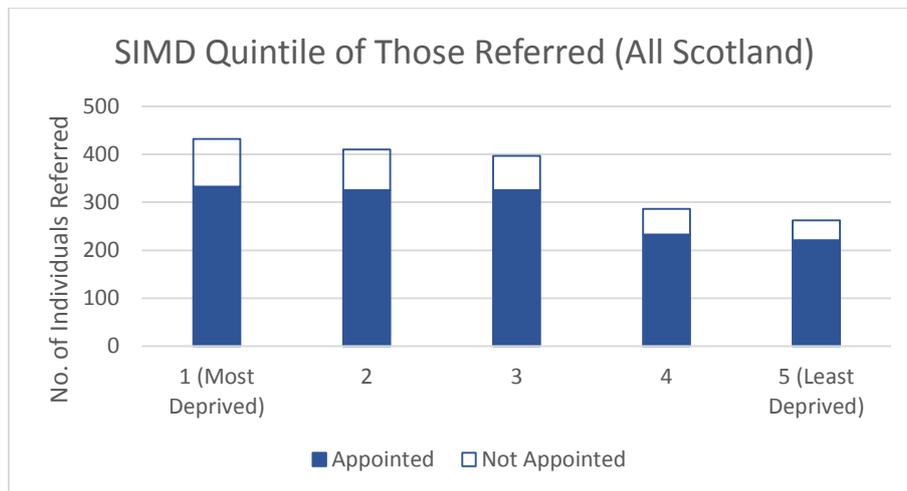
**Graph 6: Average Waiting Time to 1<sup>st</sup> Appointment (All Scotland)**



The mean waiting time for adult GICs fell by 69.2% across the time period, from 370.8 days in 2014 to 114.3 days in 2017. The median and maximum number of days individuals spent waiting for an appointment for the service also markedly reduced throughout the same period. However, the degree of reduction in 2017 should be interpreted with caution, as this only includes the 9.8% of referrals to the Sandyford GIC who had received appointments at the time of data collection, so may not be directly comparable with previous years. The reduction in waiting times across the time

period was shown to be statistically significant both when those not appointed were excluded (82.3 days/year, 95% CI 75.7-88.9 days,  $p < 0.001$ ) and included (78.7 days, 95% CI 73.4-84.0,  $p < 0.001$ ). Finally, Graph 7 demonstrates the deprivation profile of those referred to adult GICs across the whole period.

**Graph 7: SIMD Quintile of Referrals (All Scotland)**



There is a socioeconomic gradient in those referred to adult GICs from 2014 to 2017, with more individuals referred from more deprived quintiles.

**National Data – Young Person’s Gender Identity Clinic**

The data for the Young Person’s clinic at Sandyford carry similar limitations as those discussed for the data above, which should be considered in their interpretation. Additionally, it is difficult to determine from the Sandyford electronic recording system which individuals have been referred to the adult service and which have been referred to the YP service, as this is not routinely documented. Where individuals were on the age borderline between services, the decision was taken (after consultation with the YP service lead) to interpret all those aged 16 and below at referral as being referred to the YP service, unless it was explicitly recorded that they were referred to the adult service.

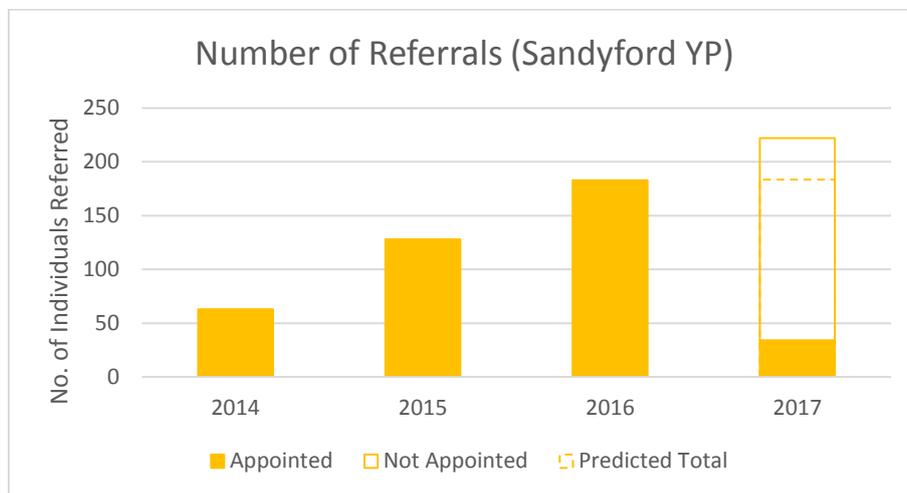
Table 5 shows the number of referrals to the YP service in each included year, alongside the annual percentage change in referral numbers. For 2017, the total number of pending referrals are shown alongside the predicted number of likely accepted referrals, with percentage change displayed for both figures (based on the 2015 acceptance rate of 79.5%). Referral acceptance rates for the YP service have historically been higher than the Sandyford adult service, with percentage of referrals received which were not appointed being 7.4% in 2014 and 20.5% in 2015. As there were still some 2016 referrals to the YP clinic waiting to be reviewed at the time of data extraction, an acceptance rate could not be accurately calculated for this year.

**Table 5: Number of Referrals and % Change (Young People, All Scotland)**

Year	Appointed Referrals	Pending Referrals	% Change
2014	63		
2015	128		+103.2%
2016	183		+43.0%
2017	34	188 (79.5% = 149) Total: <u>222</u> (183)	+21.3% (0.0%)

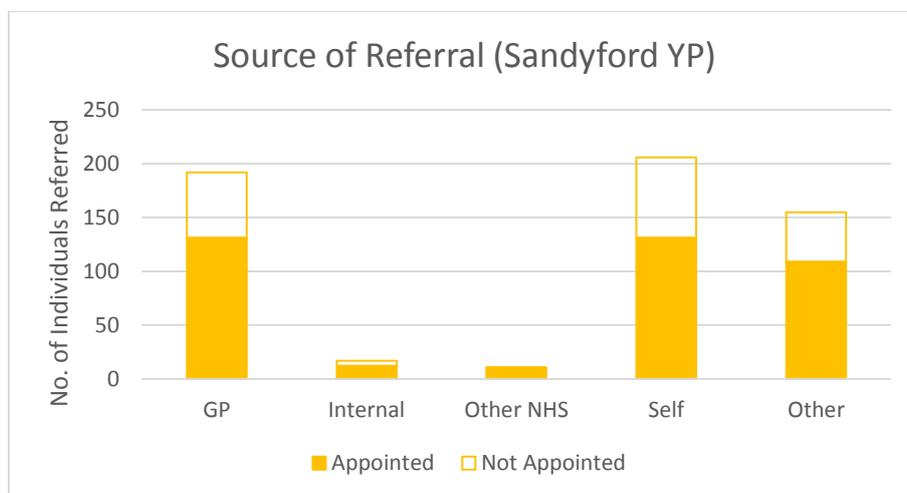
As with adult services, there has been an increase in referrals in all years, but with the rate of increase slowing over time. Assuming there is no significant change in the acceptance rate for referrals, it is likely that the number of appointed referrals in 2017 will be similar to 2016 (183 vs 183). These figures are also illustrated in Graph 8.

**Graph 8: Number of Referrals (Young People, All Scotland)**



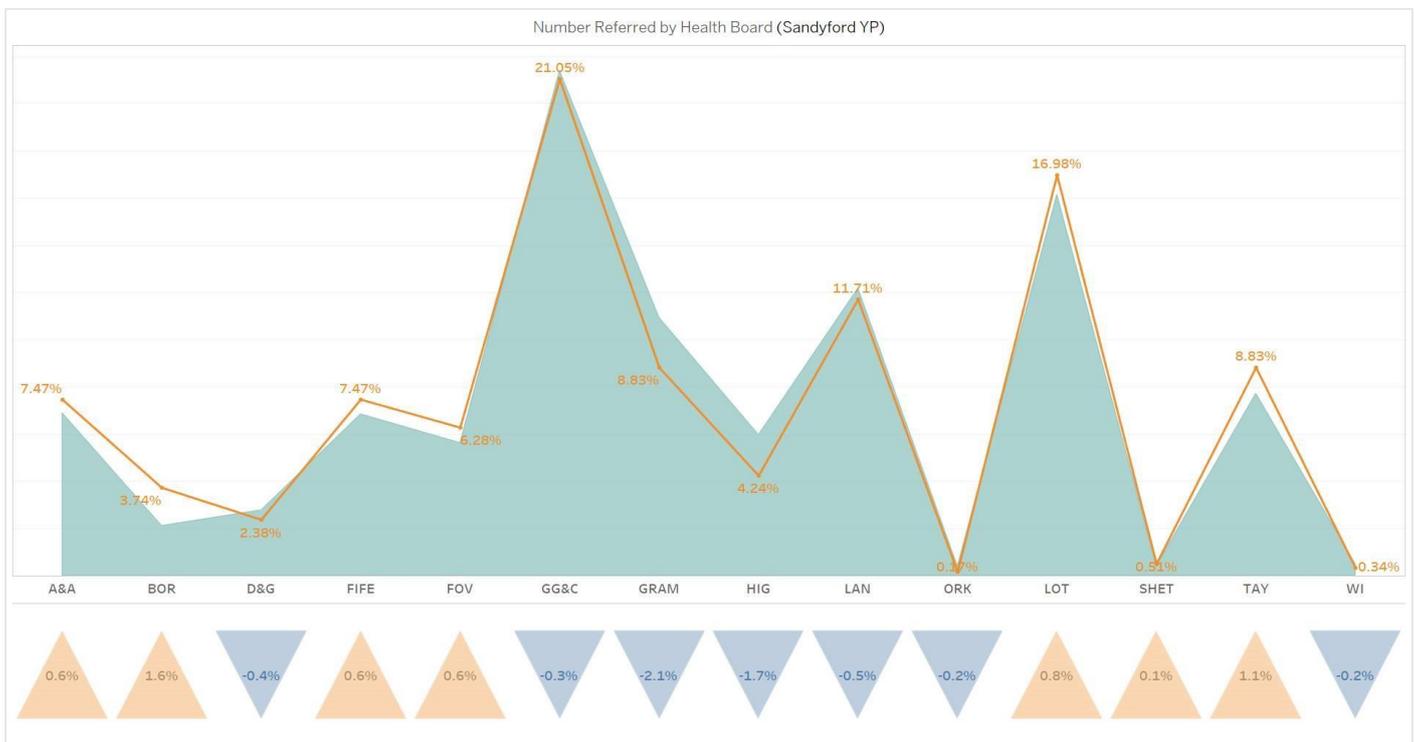
Of the referrals received by the YP service in 2017, 84.7% have yet to be appointed. Graph 9 shows the source of all referrals to the YP service across the four year period.

**Graph 9: Source of Referrals (Young People, All Scotland)**



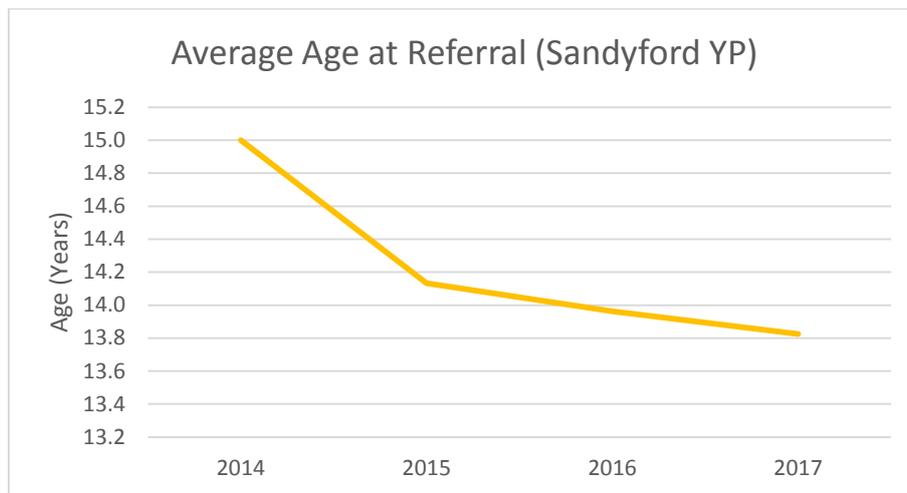
The majority of referrals to the service are by self-referral (35.5%) or via a General Practitioner (33.0%). 26.7% of all referrals were coded as 'other', which could include referral from private services or from schools. A markedly smaller number of referrals were received from either internal (other GICs) or other NHS sources, 2.9% and 1.9% respectively, which is in keeping with the younger age of patients and the fact the Sandyford YP clinic is the sole GIC for young people in Scotland. Graph 10 displays the health board of origin for all referrals (trend line), alongside the relative distribution of the national population between health boards (solid area). As the YP clinic is the only centre for young people and therefore there is no missing data, it would be expected that the distribution of referrals approximates the population.

**Graph 10: Number of Referrals by Health Board (Young People, All Scotland)**



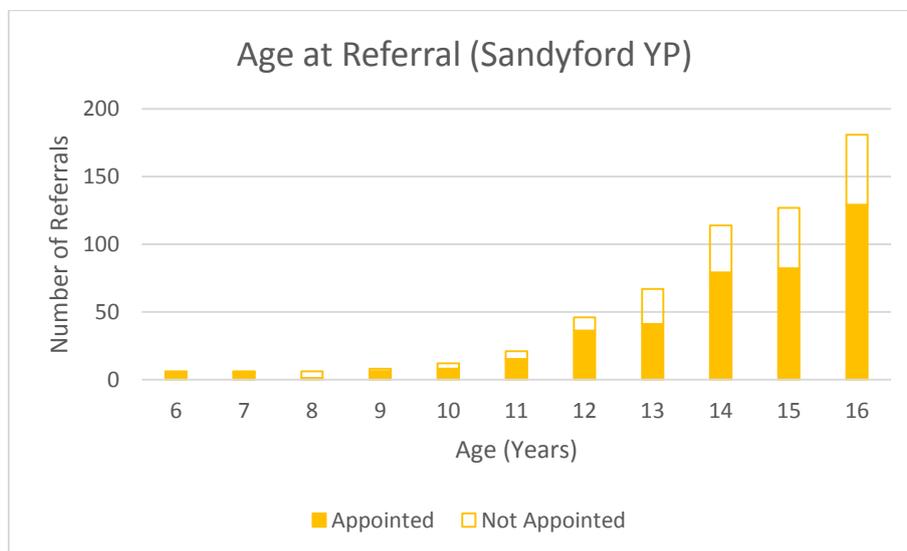
The majority of health boards (10 of 14) have referral numbers less than 1.0% different from that which would be expected based on population distribution, with representation of referrals largely mapping well to the population. Those which do differ do not do so markedly, with the largest differences being under-representations of NHS Grampian (2.1%) and NHS Highland (1.7%). The phenomenon of increased number of referrals from urban health boards seen in adults is not replicated for young people, adding weight to the hypothesis that this may be related to patient choice to relocate in adulthood. Graph 11 displays the average age of young people when they are referred to services.

**Graph 11: Average Age at Referral (Young People, All Scotland)**



The average age at referral to the YP service has fallen over time, from 15.0 years in 2014 to 13.8 years in 2017, and this decrease was shown to be statistically significant (0.3 years of age/year, 95% CI 0.1-0.5,  $p=0.001$ ). The mean age throughout the whole period was 14.1 years, with the median being 15 years. The range of ages among those from whom referrals were accepted was 6 to 16 years. Graph 12 is a histogram showing the distribution of ages of all those referred.

**Graph 12: Distribution of Age at Referral (Young People, All Scotland)**



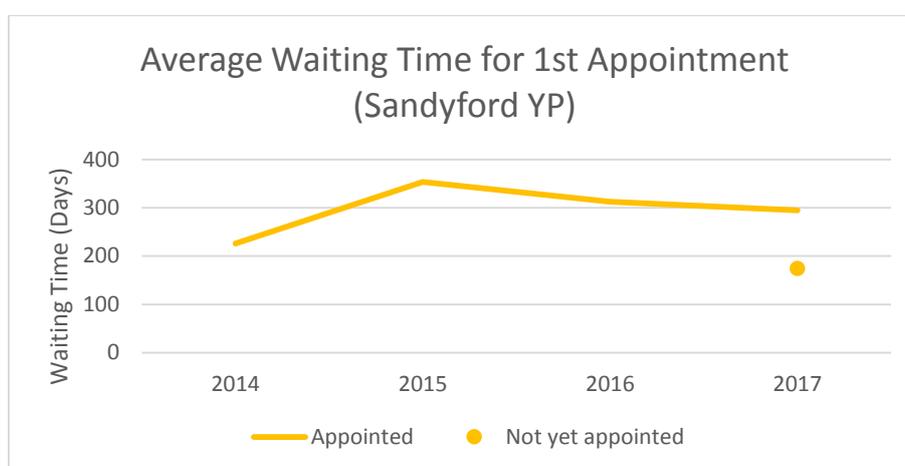
The number of children/young people referred to the service increased with increasing age, with 16 years being the most frequent age at referral (mode). Waiting times were calculated as described above. Table 6 displays the mean, median, minimum and maximum number of days individuals had to wait until their first appointment at the YP service, along with the annual percentage change in mean waiting time. For 2017 the values given are for those who have already received appointments.

**Table 6: Waiting Times by Year of Referral (Young People, All Scotland)**

Year	Mean WT	% Change	Median WT	Min. WT	Max. WT
2014	226		212	56	772
2015	353	56.56%	375	69	660
2016	312	-11.65%	329	63	733
2017	294	-5.70%	314	0	407
Whole Period	<b>310</b>	<b>-</b>	<b>316</b>	<b>0</b>	<b>772</b>

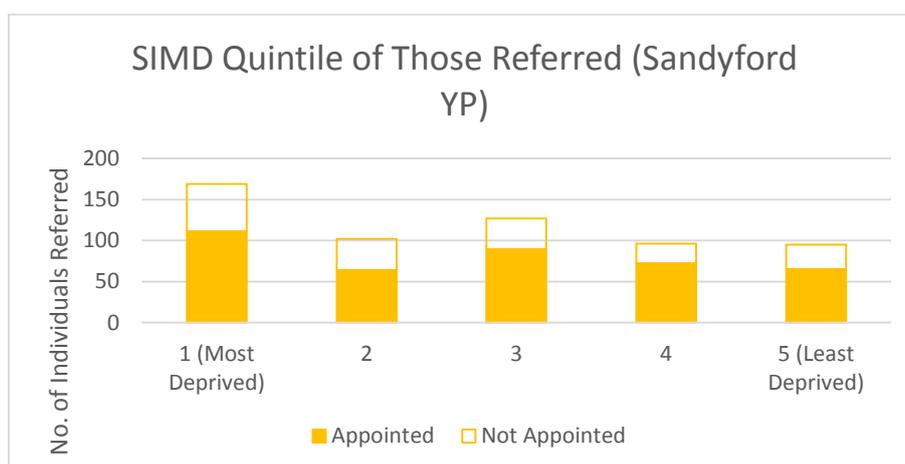
For those referred in 2017 who have not yet received appointments, the mean waiting time as of 31<sup>st</sup> December 2017 was 175 days (median 188 days, range 2-334 days). The change in average (mean) waiting time is displayed in Graph 13.

**Graph 13: Average Waiting Time to 1<sup>st</sup> Appointment (Young People, All Scotland)**



There was a marked increase in mean and median waiting time from 2014 to 2015. Since then there has been a consistent decrease in annual waiting time, though the degree of change has reduced. The minimum and maximum number of days individuals wait for a first appointment has fluctuated throughout the period, with no clear trend established. Linear regression was not performed as there was not a clear linear relationship. Finally, Graph 14 demonstrates the deprivation profile of those referred to the YP service across the whole period.

**Graph 14: SIMD Quintile of Referrals (Young People, All Scotland)**



There is a notable over-representation of those in the most deprived quintile, with representation across deprivation quintiles otherwise seemingly fairly evenly distributed with no clear gradient.

### National Data – Gender Reassignment Surgery

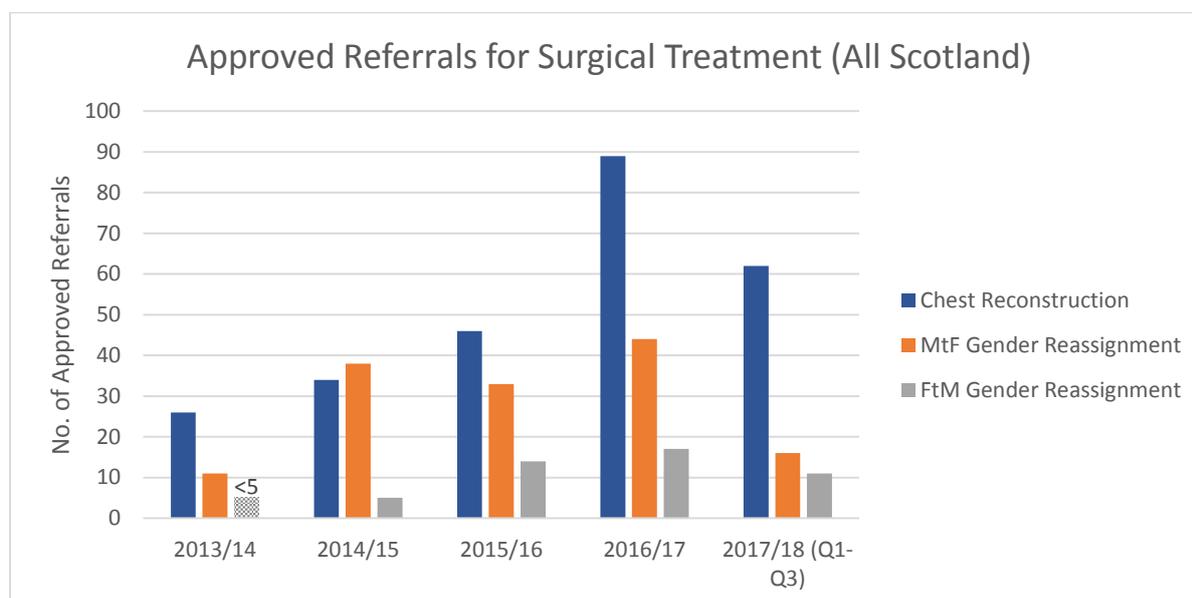
Data on gender reassignment surgery were provided by the NHS National Services Division (NSD) and include all approved referrals for gender reassignment surgeries since the financial year 2013/14, including the first three quarters of financial year 2017/18. It is noted that these figures refer only to the number of approved referrals, not the number of completed surgeries. However, definitive information on completed surgeries is not available until NHS England provides details of costs incurred to NSD for payment which can take many months, therefore the number of approved referrals per financial year was felt to be a reasonable and timely proxy. The data are displayed in Table 7 stratified by type of surgery with annual percentage change (for 2017/18 this has been adjusted to account for the shorter time period), as well as the overall percentage change throughout the whole period. The number of approved referrals for masculinising lower surgery in 2013/14 has not been shown for confidentiality reasons, as this totalled less than 5.

**Table 7: Approved GRS Referrals and % Change (All Scotland)**

	2013/ 14	2014/15	2015/16	2016/17	2017/18 (Q1-Q3)	% Change 2013- 2018
Chest Reconstruction	26	34	46	89	62	
<i>% change</i>		30.8%	35.3%	93.5%	-7.1%	217.9%
Feminising Lower Surgery	11	38	33	44	16	
<i>% change</i>		245.5%	-13.2%	33.3%	-51.5%	93.9%
Masculinising Lower Surgery	<5	5	14	17	11	
<i>% change</i>		0.0%	180.0%	21.4%	-13.7%	193.3%

The number of referrals for surgical intervention approved by NSD has risen in all categories from 2013/14. The degree of change is most notable for chest reconstruction surgery and FtM gender reassignment surgery, each increasing around threefold. These data are also presented in Graph 15.

**Graph 15: Approved Referrals for Surgical Treatment (All Scotland)**



Approved referrals for the surgery most likely to be undertaken by trans feminine individuals (MtF gender reassignment) increased considerably in 2014/15, then plateaued before reducing markedly in 2017/18. Conversely, approved referrals for surgeries likely to be undertaken by trans masculine individuals (chest reconstruction, FtM gender reassignment) peaked at a later point in 2016/17. While referrals for these two operations also decreased in 2017/18, the reduction was to a lesser extent than for feminising lower surgery. It is worth noting however that 2017/18 data only include three quarters of the year, and there may be an element of seasonal variability in referrals. Numbers could also have been affected by recent changes in GIC staffing, particularly with one referring clinician taking a planned absence from the service, potentially postponing some referrals until their return.

### Local Data – Sandyford GIC

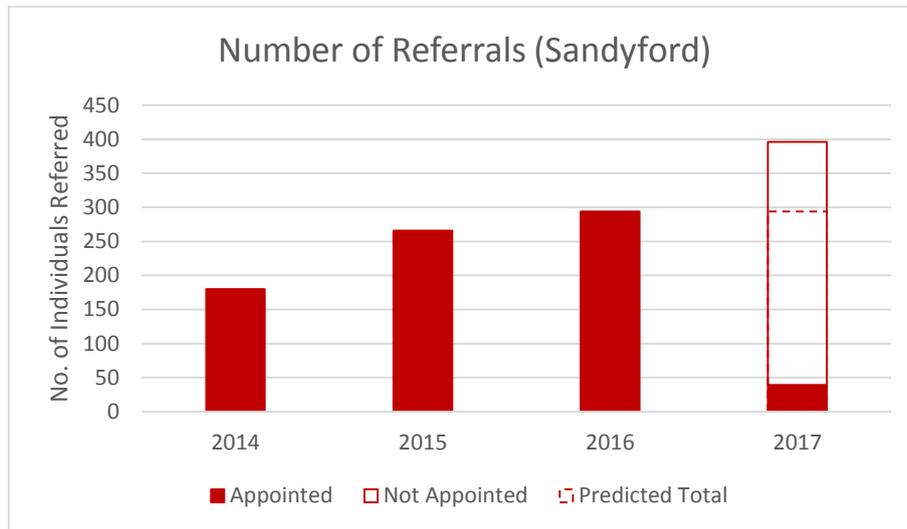
Table 8 shows the number of accepted referrals to the Sandyford GIC from January 2014 to December 2017, alongside the annual percentage change in referral numbers. For 2017, the total number of pending Sandyford referrals are shown alongside the predicted number of likely accepted referrals (based on 2016 acceptance rate of 71.4%), with percentage total change displayed for both figures.

**Table 8: Number of Referrals and % Change (Sandyford GIC)**

Year	Appointed Referrals	Pending Referrals	% Change
2014	180		
2015	266		+47.8%
2016	294		+10.5%
2017	39	357 (71.4% = 255)	+34.7% (+0.0%)

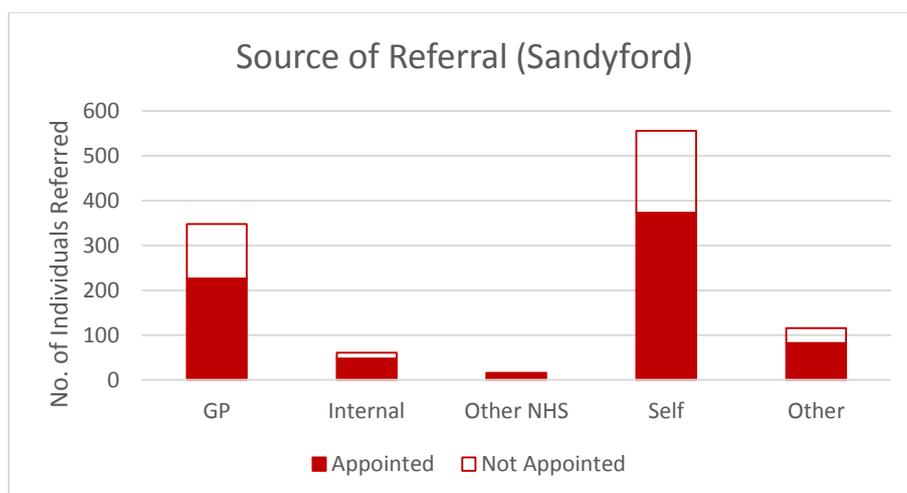
In total, 1136 individuals were referred to the Sandyford GIC during the period for which data were available (with the predicted total after pending referrals from 2017 are processed being 1034). The number of annual referrals increased by 120.0% (predicted actual increase 63.3%) from 2014 to 2017. These figures are also illustrated in Graph 16.

**Graph 16: Number of Referrals (Sandyford GIC)**



In keeping with the national trend, there has been an increase in referrals in all years, but with the rate of increase slowing over time. This slowing has been more marked than the national picture, with the predicted total of individuals likely to be appointed being 294 in 2017, the same as it was in 2016 (based on the assumption that referral acceptance rates remain the same). Of those referred to the Sandyford GIC in 2017, 90.2% have yet to be appointed. Graph 17 shows the source of all referrals to the Sandyford service across the four year period.

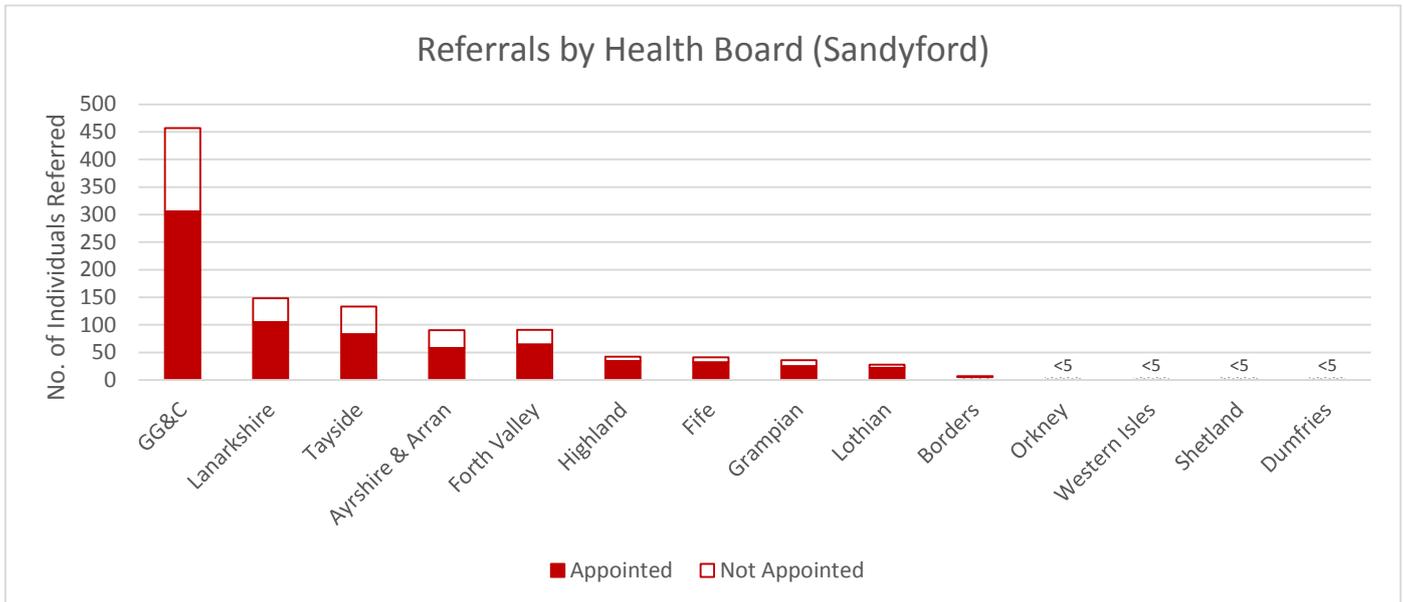
**Graph 17: Source of Referrals (Sandyford GIC)**



The majority of referrals to the service are self-referrals (50.7%), with referral via a General Practitioner the next most likely route (31.7%). Smaller numbers were referred from other GICs (5.6%) and other NHS services (1.5%), with the remaining referrals

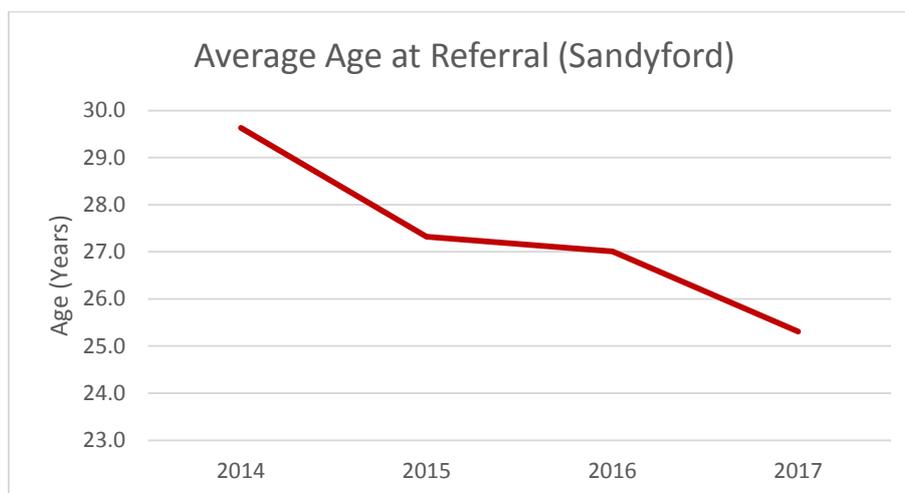
coming from a variety of other sources (10.6%). When broken down by year the respective contribution of each source over time was extremely similar to the national trend. Graph 18 displays the health board of origin for all referrals.

**Graph 18: Number of Referrals by Health Board (Sandyford GIC)**



The largest proportion of referrals to the Sandyford GIC from 2014 to 2017 were for individuals residing within NHS Greater Glasgow and Clyde (42.1%), followed by NHS Lanarkshire (13.6%), NHS Tayside (12.2%), NHS Ayrshire and Arran (8.3%), and NHS Forth Valley (8.4%). Smaller numbers were referred from the remainder of the fourteen health boards; those boards which totalled less than five referrals in the four year period are not shown for confidentiality reasons. Graph 19 displays the average age of individuals at the point where they are referred to services.

**Graph 19: Average Age at Referral (Sandyford GIC)**



The annual average (mean) age of those referred fell continuously from 29.6 years in 2014 to 25.3 years in 2017, in keeping with the national trend. This was shown to be

statistically significant (reduction by 1.3 years of age/year, 95% CI 0.7-1.9 years,  $p < 0.001$ ). The mean age of all individuals referred to the Sandyford GIC from 2014 to 2017 was 26.9 years (median 22 years, range 15-77 years).

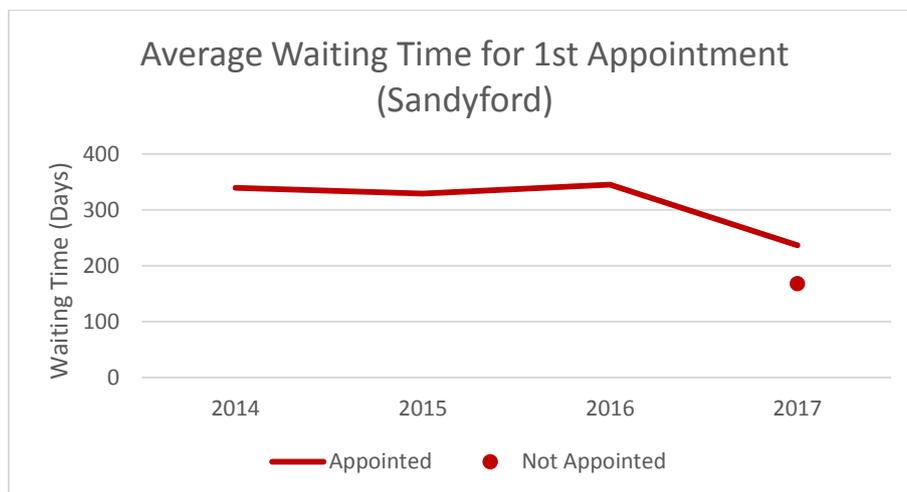
Waiting times were calculated as described above. Table 9 displays the mean, median, minimum and maximum number of days individuals had to wait until their first appointment at the Sandyford GIC, along with the annual percentage change in mean waiting time. For 2017, only the waiting times of those who have received appointments have been included.

**Table 9: Waiting Times by Year of Referral (Sandyford GIC)**

Year	Mean WT	% Change	Median WT	Min. WT	Max. WT
2014	340		350	46	647
2015	329	-3.06%	363	10	541
2016	345	4.82%	359	1	555
2017	237	-31.39%	239	5	407
Whole Period	<b>333</b>	-	<b>359</b>	<b>1</b>	<b>647</b>

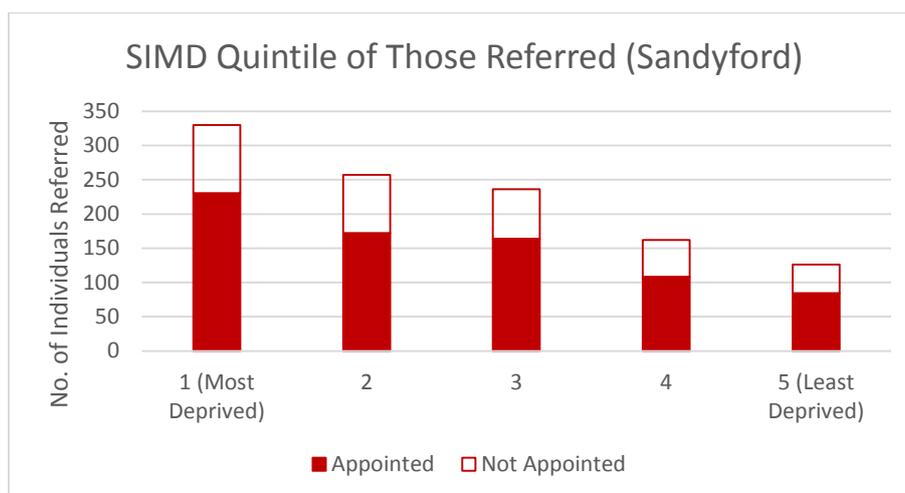
The average (mean) waiting time remained similar from 2014 to 2016, as did the median, which is not in keeping with the national trend of a decrease in waiting times; the maximum number of days waited for an appointment did however reduce by 14.2%. There was a marked reduction in mean, median and maximum waiting times in 2017, however as this only represents those who had already been appointed (9.8% of all 2017 referrals) it is not directly comparable with previous years. The change in average waiting time is displayed in Graph 20.

**Graph 20: Average Waiting Time to 1<sup>st</sup> Appointment (Sandyford GIC)**



In all years except 2014, the mean waiting time for Sandyford GIC was higher than the national average. For those 2017 referrals who had yet to be appointed, the mean waiting time to 31 December 2017 was 168.4 days (median 179 days, range 2-341 days). Regression analysis was not performed as there was no evidence of a linear relationship. Finally, Graph 21 demonstrates the deprivation profile of those referred to the Sandyford GIC across the whole period.

**Graph 21: SIMD Quintile of Referrals (Sandyford GIC)**



There is a clear socioeconomic gradient in those referred to the Sandyford GIC from 2014 to 2017, with more individuals referred from more deprived quintiles. It is likely this is at least in part due to the demography of NHS Greater Glasgow and Clyde where the largest proportion of patients are from, but it is not clear to what extent this explains the phenomenon.

### Local Data – Lothian GIC

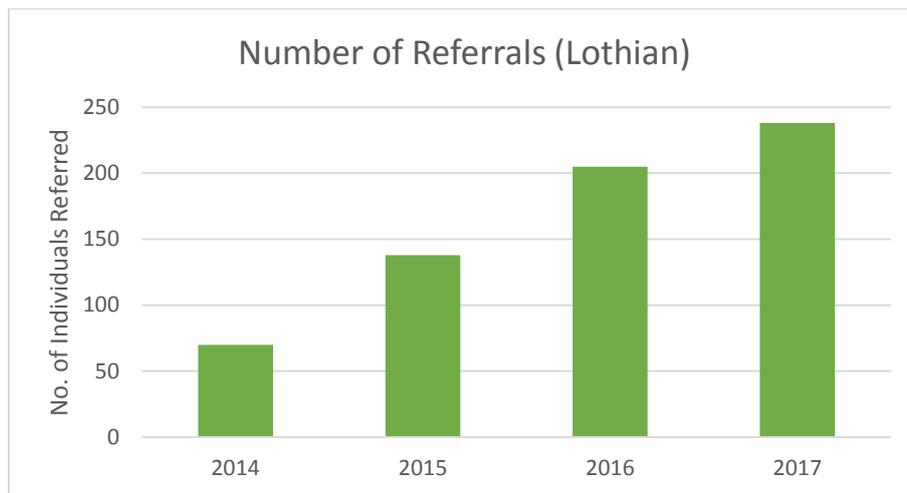
Table 10 shows the number of accepted referrals to the Lothian GIC from January 2014 to December 2017, alongside the annual percentage change in referral numbers. Any individuals referred and *not* appointed were not included as these data were unavailable, however the service does not routinely refuse referrals unless individuals are under 18, in which case they are directed to the Sandyford YP service.

**Table 10: Number of Referrals and % Change (Lothian GIC)**

Year	Appointed Referrals	% Change
2014	70	
2015	138	+97.1%
2016	205	+48.6%
2017	238	+16.1%

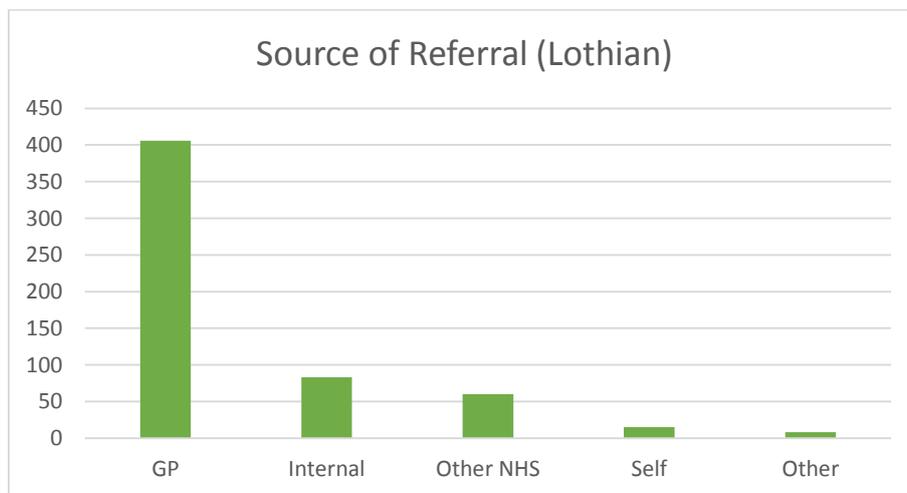
In total, 651 individuals were referred to the Lothian GIC during the period for which data were available. The number of annual referrals increased by 240.0% from 2014 to 2017. These figures are also illustrated in Graph 22.

**Graph 22: Number of Referrals (Lothian GIC)**



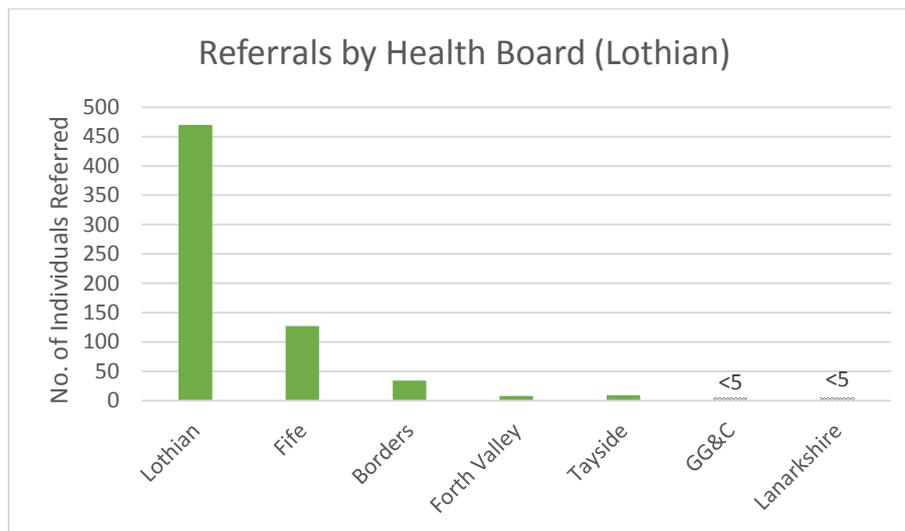
In keeping with the national trend, there has been an increase in referrals in all years, but with the rate of increase slowing over time. Graph 23 shows the source of all referrals to the Lothian service across the four year period.

**Graph 23: Source of Referrals (Lothian GIC)**



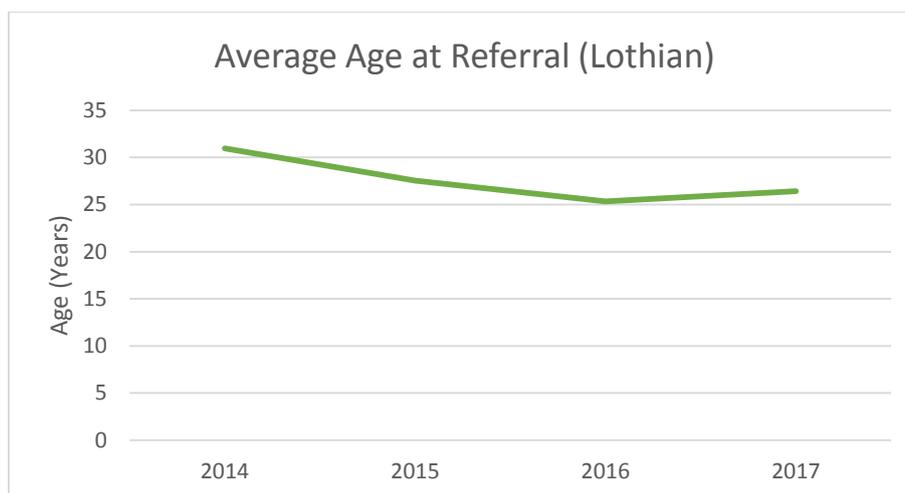
The majority of referrals to the service are via a General Practitioner (71.0%), with referral from another GIC (14.5%) or other NHS services (10.5%) being the next most likely sources. Only 2.6% of all referrals were self-referrals, which is in keeping with the Lothian GIC policy of requiring individuals to approach their GP for referral. The 1.4% of referrals from 'Other' sources were all referrals from private practice. When broken down by year numbers in several categories were too small to report, but no discernible change in source was noted over time. Graph 24 displays the health board of origin for all referrals.

**Graph 24: Number of Referrals by Health Board (Lothian GIC)**



The vast majority of referrals to the Lothian GIC from 2014 to 2017 were for individuals residing within NHS Lothian (72.3%). Those residing in NHS Fife (19.5%) and NHS Borders (5.2%) made up most of the rest of the referrals, which would be expected as these health boards have formal arrangements to refer to Lothian GIC. Smaller numbers were reported from NHS Forth Valley, NHS Tayside, NHS GG&C, and NHS Lanarkshire; the latter two boards totalled less than five and exact numbers are therefore not shown for confidentiality reasons. Graph 25 displays the average age of individuals at the point where they are referred to services.

**Graph 25: Average Age at Referral (Lothian GIC)**



The annual average (mean) age of those referred fell from 31.0 years in 2014 to 25.3 years in 2016, rising slightly again to 26.4 years in 2017. This is out of keeping with the national trend, where average age at referral has fallen continuously throughout the study period; as the relationship was not linear in this case, regression analysis was not performed as the assumptions for this test would not be met. The mean age

of all individuals referred to the Lothian GIC from 2014 to 2017 was 26.8 years (median 23 years, range 14-93 years).

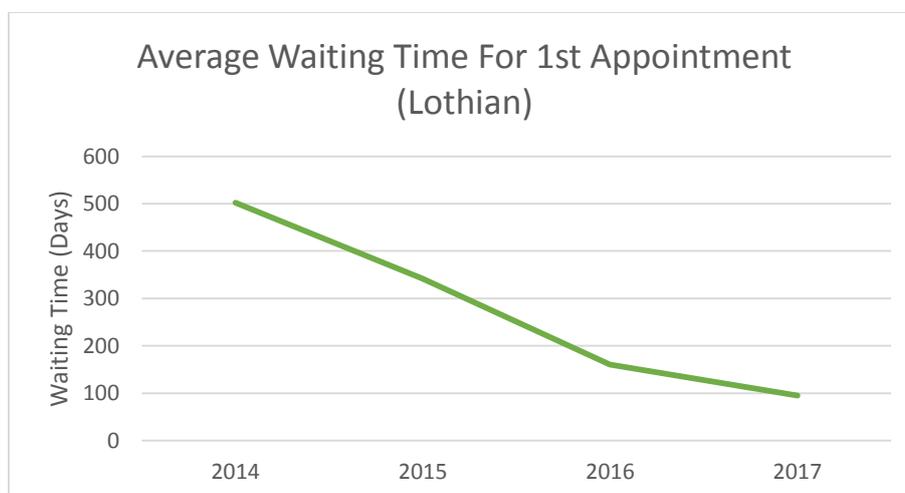
Waiting times were calculated as described above. Table 11 displays the mean, median, minimum and maximum number of days individuals had to wait until their first appointment at the Lothian GIC, along with the annual percentage change in mean waiting time.

**Table 11: Waiting Times by Year of Referral (Lothian GIC)**

Year	Mean WT	% Change	Median WT	Min. WT	Max. WT
2014	502		601	48	943
2015	342	-31.92%	358	65	575
2016	160	-53.08%	175	0	544
2017	95	-40.87%	92	0	294
Whole Period	<b>212</b>	-	<b>146</b>	<b>0</b>	<b>943</b>

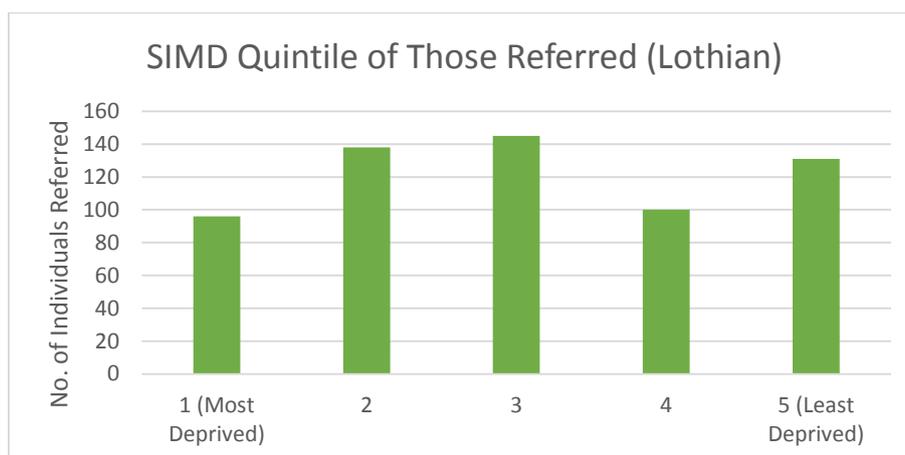
The average (mean) waiting time fell by 81.1% across the time period, from 502.1 days in 2014 to 94.8 days in 2017. The median and maximum number of days individuals spend waiting for an appointment for the service has also consistently reduced throughout the same period. The change in average waiting time is displayed in Graph 26.

**Graph 26: Average Waiting Time to 1<sup>st</sup> Appointment (Lothian GIC)**



In both 2014 and 2015, the mean waiting time for Lothian GIC was higher than the national average, however the consistent marked decrease over time has meant that in 2016 and 2017 the service had a waiting time below the national average. The reduction in waiting times across the time period was shown to be statistically significant (132.2 days/year, 95% CI 123.9-140.6 days,  $p < 0.001$ ). Finally, Graph 27 demonstrates the deprivation profile of those referred to the Lothian GIC across the whole period.

**Graph 27: SIMD Quintile of Referrals (Lothian GIC)**



There is no clear socioeconomic gradient in those referred to the Lothian GIC from 2014 to 2017.

**Local Data – Highland GIC**

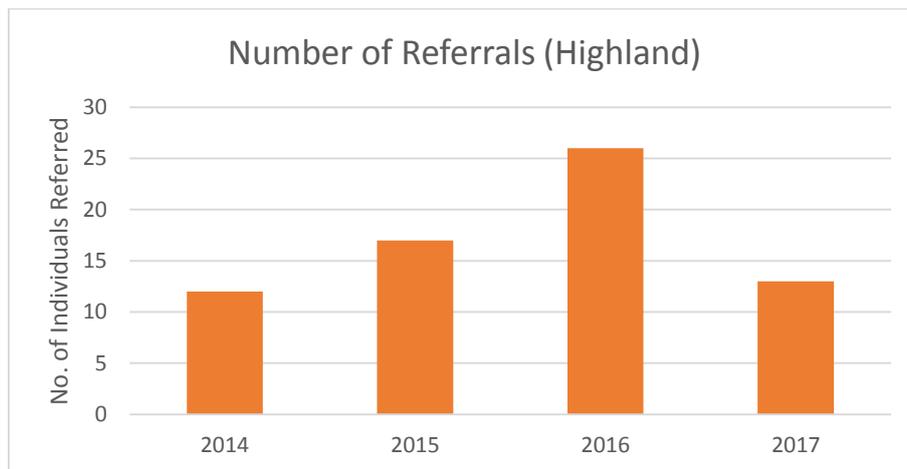
Table 12 shows the number of accepted referrals to the Highland GIC from January 2014 to November 2017, alongside the annual percentage change in referral numbers. Any individuals referred and *not* appointed were not included as these data were unavailable, however the service does not routinely refuse referrals unless individuals are under 18, in which case they are directed to the Sandyford YP service, or from another health board, in which case they are redirected to the appropriate service.

**Table 12: Number of Referrals and % Change (Highland GIC)**

Year	Appointed Referrals	% Change
2014	12	
2015	17	+41.7%
2016	26	+52.9%
2017	13	-50.0%

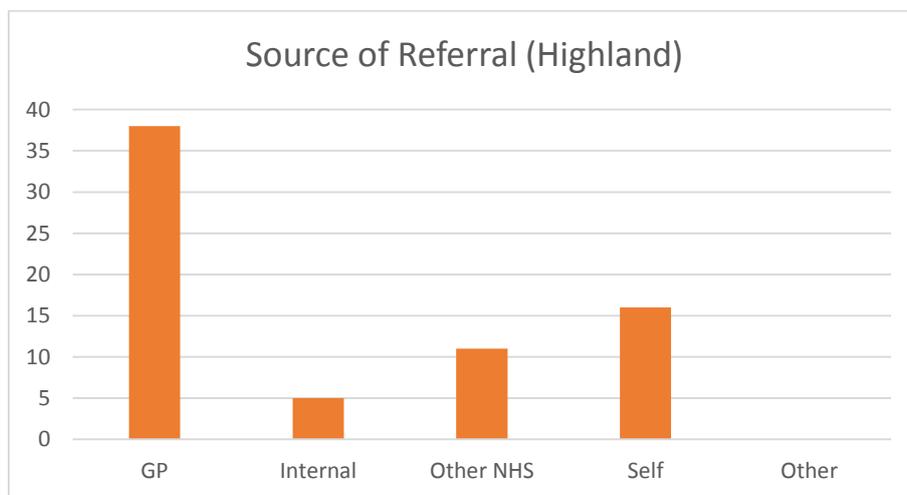
In total, 68 individuals were referred to the Highland GIC during the period for which data were available. The number of annual referrals increased by 116.7% from 2014 to 2016, which is in keeping with the national trend. However, there was a subsequent 50.0% decline to 13 referrals in 2017, going against the national trend. These figures are also illustrated in Graph 28.

**Graph 28: Number of Referrals (Highland GIC)**



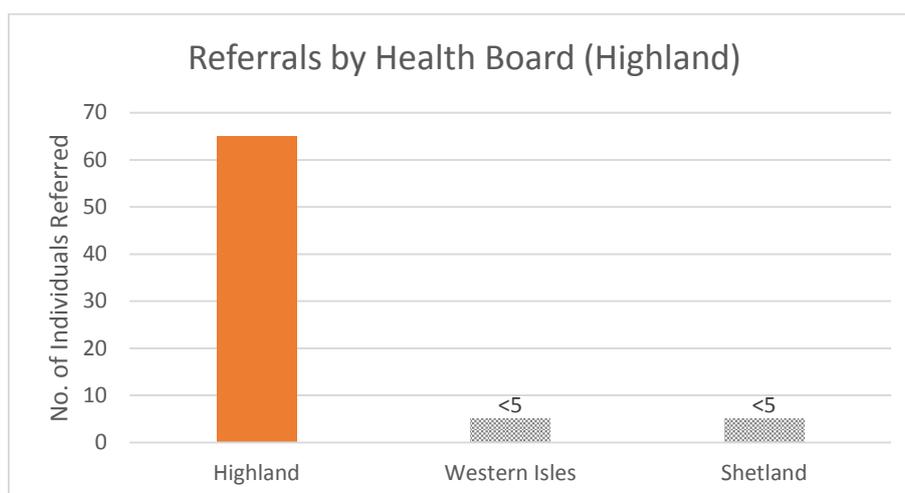
Given the relatively small numbers of individuals attending the Highland clinic in comparison to the larger GICs, care should be taken in interpreting these trends, given the increased likelihood that they may be due to chance. Graph 29 shows the source of all referrals to the Highland service across the four year period.

**Graph 29: Source of Referrals (Highland GIC)**



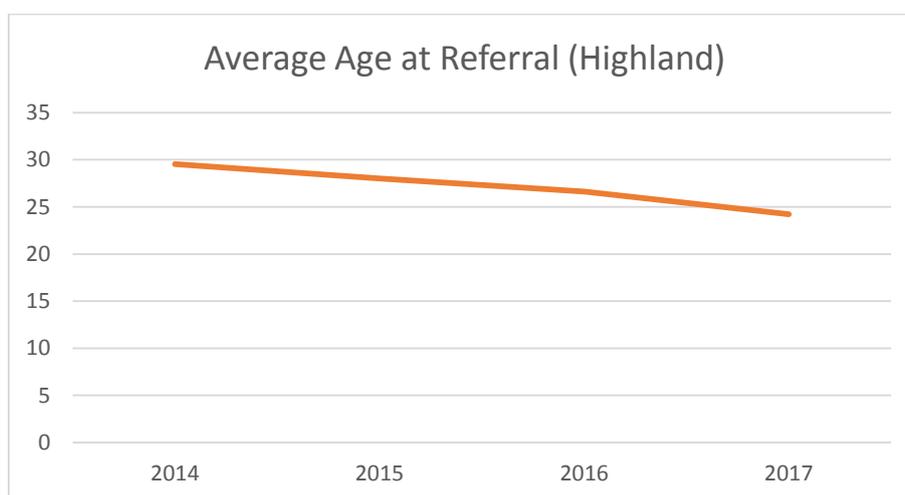
The majority of referrals to the service are via a General Practitioner (54.3%), followed by self-referral (22.9%) and referrals from other NHS services (15.7%). A smaller number (7.1%) were referred from another GIC, and there were no referrals from any other sources. When broken down by year numbers in several categories were too small to report or indicate any clear trend. Graph 30 displays the health board of origin for all referrals.

**Graph 30: Number of Referrals by Health Board (Highland GIC)**



The overwhelming majority of referrals to the Highland GIC from 2014 to 2017 were for individuals residing within NHS Highland (95.6%), which is to be expected as the current referral pathway states this is a requirement for access to the service. A very small number of referrals received were for individuals residing in NHS Western Isles or NHS Shetland, and were a mixture of self-referrals to the service and referrals from other GICs where more local provision may have been indicated. As these occasions totalled less than five individuals, exact numbers are not shown for confidentiality reasons. Graph 31 displays the average age of individuals at the point where they are referred to services.

**Graph 31: Average Age at Referral (Highland GIC)**



The annual average (mean) age of those referred fell continuously from 29.5 years in 2014 to 24.2 years in 2017, in keeping with the national trend. Despite this the trend was not shown to be statistically significant on regression analysis (reduction by 1.7 years, 95% CI -5.0-1.5,  $p=0.29$ ) which is likely due to the small sample size. The mean age of all individuals referred to the Highland GIC from 2014 to 2017 was 27.0 years (median 21 years, range 13-60 years).

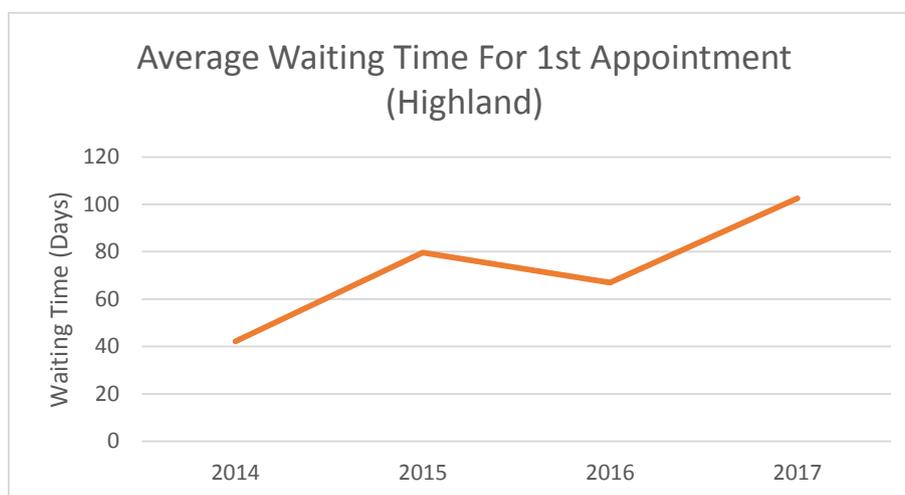
Waiting times were calculated as described above. Table 13 displays the mean, median, minimum and maximum number of days individuals had to wait until their first appointment at the Highland GIC, along with the annual percentage change in mean waiting time.

**Table 13: Waiting Times by Year of Referral (Highland GIC)**

Year	Mean WT	% Change	Median WT	Min. WT	Max. WT
2014	42		53	0	88
2015	80	+88.68%	78	0	146
2016	67	-15.87%	78	0	210
2017	103	+53.14%	76	10	227
Whole Period	<b>73</b>	<b>-</b>	<b>68</b>	<b>0</b>	<b>227</b>

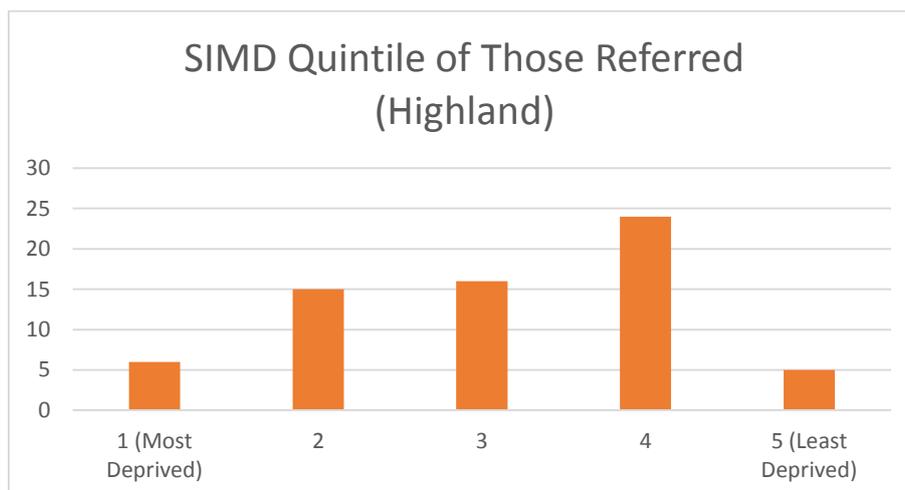
The average (mean) waiting time increased by 145.2% across the time period, from 42.2 days in 2014 to 102.5 days in 2017, in contrast with the national trend, though there was not a consistent increase in every year. The median number of days individuals spent waiting for an appointment for the service increased by 47.2% from 2014 to 2015, but then remained fairly consistent for the rest of the study period; however, the maximum number of days individuals waited increased in every year. The change in average waiting time is displayed in Graph 32.

**Graph 32: Average Waiting Time to 1<sup>st</sup> Appointment (Highland GIC)**



In every year the mean waiting time for Highland GIC was lower than the national average, though the gap between the two decreased from 328.6 days in 2014 to 11.8 days in 2017. The increase in waiting times across the time period was shown to be statistically significant, though the 95% confidence interval is very wide due to the small sample size (15.0 days, 95% CI 1.7-28.4 days,  $p < 0.001$ ). Finally, Graph 33 demonstrates the deprivation profile of those referred to the Lothian GIC across the whole period.

**Graph 33: SIMD Quintile of Referrals (Highland GIC)**



It appears that fewer referrals were made to the Highland GIC from those in the most and least deprived SIMD quintiles from 2014 to 2017 than those in quintiles two to four, however the numbers are very small and it is therefore difficult to conclude with certainty whether this is a true pattern.

### **Local Data – Third Sector Organisation**

A small amount of recent data on crude number of enquiries and support work was obtained from LGBT Health and Wellbeing, who offer trans-specific services in Glasgow and Edinburgh. Their services divide into two categories: the organisation offers one-to-one support and information via phone, email, or face-to-face to trans people or others in their lives who desire support; and the organisation offers groups, workshops, and social support for trans people and their families.

In the 2016-2017 year, the organisation’s one-to-one service provided support to 310 individuals (70% trans people, the remainder being partners, family, friends, or professionals). This marked a 34% increase in demand from the previous year.

In the same year, the organisation’s group services provided support to 268 individuals, some of whom accessed multiple activities. This represented an 87% increase in demand from the previous year, with the increase in demand being more marked in the Glasgow area where services are more recently established (125% vs 50% in Edinburgh).

### **Summary**

These analyses explored national and local referral data by year of referral, source of referral, demographic characteristics, and waiting time. The findings indicate that, nationally, numbers of referrals to GICs and for surgical interventions have increased markedly over time, but may possibly be approaching a plateau. For adults there is an over-representation of referrals to GICs from urban health boards, particularly NHS Lothian which is a notable outlier, which may be represent a true variation in the LGBTQ+ population. For young people referrals are more evenly distributed, with the

exception of slight under-representation of some remote boards. Average age at referral has fallen over time for both adults and young people.

Nationally, waiting times for adult GICs have decreased over time, though this varies by clinic with waiting times falling markedly at Lothian GIC, being fairly consistent at Sandyford GIC, and actually increasing at Highland GIC. Waiting times for young people have increased over the same time period. Data were unavailable from Grampian GIC due to a lack of consistent service provision and data collection during the time period of interest. A socioeconomic gradient in referrals to adult GICs was noted, which was most marked in those attending Sandyford GIC. For young people there was an over-representation of those from the most deprived quintile, but no socioeconomic gradient.

### What Does This Mean For Us?

While it looks like the increase in the number of trans people presenting to gender identity clinics in Scotland might be slowing, the rate of change is not completely predictable. Waiting times for most services are long, and it is likely that services will need to increase or change their way of working to meet the current level of need and reduce these waiting times. The model in place at Lothian GIC seems to have been effective in reducing waiting times, despite this clinic having a greater percentage increase in referral numbers.

More trans adults are accessing services from health boards in cities than in more remote areas, particularly Edinburgh which is over-represented. It is likely this is related to trans people moving where they know that there are services and communities to support them. Third sector colleagues working in Scotland were able to give many examples of trans people who said they had done this, and Edinburgh in particular is known to be the city with the most established trans support groups and shortest waiting times for NHS services. While it is good that existing services are popular, it is extremely important to make sure gender identity services are equally available in all parts of Scotland, so that people are not disadvantaged based on where they live or whether they can afford to move or travel.

## Chapter 4: Corporate Needs Assessment

### Service Provider & Stakeholder Views

Interviews were conducted with twenty-eight individuals either directly involved in gender identity services or with a special interest in transgender healthcare issues in Scotland. Included were staff from three Scottish GICs, one further GIC in England, other Scottish NHS services, services outwith the NHS, and third sector bodies who work with trans people and their families in Scotland. There was representation from seven of the fourteen Scottish health boards, including four without their own dedicated GIC, as well as individuals whose remit would include cross-board cover (e.g. national third sector organisations). Those interviewed represented a range of disciplines and backgrounds, including psychiatry, psychology (clinical and educational), sexual health, general practice, speech and language therapy, equality and diversity, and advocacy.

Responses to the interview questions were aggregated and summarised with no distinction as to which organisation individuals worked for in order to preserve anonymity. Where specific examples of practice were given which proved helpful in illustrating themes in responses, the individual respondent who provided this was not identified. The responses are presented here structured around the key questions asked. Questions were slightly adapted according to which organisation interviewees worked for, however each interview covered the vast majority of the key questions summarised here.

### What is the current pathway through services for people accessing gender identity services in your area? Which services are able to be provided locally?

Answers to these questions varied considerably according to where interviewees were based, and so to provide an overview responses have been split into 'Areas with a local GIC' and 'Areas without a local GIC'.

#### Areas with a Local GIC

Each GIC differed in their approach to referral pathways as has been detailed previously, with some accepting self-referrals and some requiring referral from a General Practitioner, and both the assessment process and treatment pathways also differ between sites.

At Sandyford GIC, adults and young people have an initial assessment with a clinical psychologist (which may involve multiple appointments) before being referred on to other services as required, e.g. medical assessment for hormone treatments, counselling etc. There is a further waiting time before these subsequent assessments or interventions, and it was expressed by some respondents that counselling and family support in particular are felt to be under-provided at present. Individuals starting hormone treatment will require a medical assessment and further regular follow-up appointments. In the young person's service, pre-pubertal children, e.g. 9 or 10 year

olds, are offered telephone advice; adolescents starting puberty blocking treatments will see a paediatric endocrinologist; over the age of 16, young people may be started on gender affirming hormones following another independent assessment. As patients approach 18 years old they are referred to the adult service.

At Chalmers GIC, adults have their initial and most subsequent appointments with a specialist gender nurse. Following their initial assessment over several appointments, the specialist nurse then discusses their case at a multi-disciplinary team (MDT) meeting. A decision is taken by the MDT on whether to begin medical interventions such as hormone treatment, and regular follow-up appointments would then be arranged. At Highland GIC, all initial and subsequent assessments are performed by a consultant physician, who takes decisions about the requirement for medical treatment and liaises with the Sandyford GIC for second opinions in relation to this.

### **Areas without a Local GIC**

There were a wide variety of responses from interviewees based in areas which do not have a local GIC. Several health boards did not have any trans-specific services available, with all support being provided through links with GICs. Interviewees from these boards expressed that there was a desire to improve upon this provision locally, particularly for individuals awaiting initial assessment or requiring to travel long distances for tasks which could be performed in their home board such as hair removal, phlebotomy, and counselling. However, it was expressed that there is not a clear route to act on this, and that it would require the cooperation of GICs in moving some services away from their centres; it was felt that this could be challenging and possibly met with resistance, due to the feeling that gender identity is currently seen as a highly specialist service.

Contrastingly, NHS Tayside offers the previously outlined 'hub and spokes' model. This is an explicit local pathway shared with GPs and service users, and involves an initial referral to the local Community Mental Health Team (CMHT) prior to referral to GIC. It is not designed to act as a gatekeeping service or barrier to GIC, but rather to provide access to preliminary local services such as speech and language therapy (SALT) and hair removal services, to assist trans people in achieving some of the required 'lived experience' prior to GIC assessment. It also allows access to local counselling, and treatment for any underlying mental health conditions which may delay access to GIC treatment at a later point. At present the Tayside model does not allow for the provision of hormones locally.

The important contribution of community and primary care services to the pathway through gender identity services was discussed by many respondents regardless of their area. Most interviewees mentioned the importance and availability of third sector and voluntary support for trans people and their families, particularly in boards without a GIC. It was described that such services are often the only available option for individuals to access while waiting for specialist assessment, and also are more often accessible online e.g. through use of chatboxes which can increase the likelihood of

young trans people in particular engaging with them. In NHS Lothian there is explicit commissioning of specific voluntary sector organisations to provide additional services such as counselling and support groups for trans people, and several respondents mentioned that this partnership has been extremely successful.

### **What proportion of patients complete the pathway or start gender reassignment treatment? Has this changed?**

Answers to this question were based on the subjective impression of those who felt able to comment. Most respondents agreed that, following initial appointment at a GIC, a large proportion of adult patients will go onto some form of hormone treatment, estimating that this value was somewhere between 70% and 90%. In relation to surgery, it was agreed by several participants that the majority of binary trans men will have some form of chest surgery (estimates ranging from 80-100%) but a much smaller proportion will have masculinising genital surgery (estimates ranging from 5-25%). Respondents were less in agreement on how many binary trans women they estimated underwent feminising genital surgery, giving values ranging from 30% to 80%. Procedures undergone by those with a non-binary gender identity were discussed to be variable according to the needs and wishes of the individual. It was stressed by some respondents that trans individuals of all gender identities have a diverse range of needs, and that someone's desire for different kinds of treatment may not necessarily be aligned with how male or female they feel, therefore individualised treatment plans are required rather than a 'one size fits all' approach.

It was noted that forming impressions of long-term trends in how individuals navigate the gender reassignment pathway is complex partly due to the fact that, for most trans people who access a GIC, episodes of care from first referral to their chosen endpoint can take many years. There was further discussion that, as GICs do not routinely collect data on or report outcomes for patients, it is even more difficult to establish definitively how individuals use the pathway in practice. It was voiced by one respondent that the very phrasing of the question asking how many people 'complete the pathway' betrays a very medicalised way of considering the process, rather than taking a person-centred approach that recognises the nuanced needs of individuals. It was also noted that a significant proportion of trans people do not seek medical help through the gender reassignment pathway at all. These individuals may however still experience broader health and support needs in relation to their transgender identity, including a need for counselling, and third sector initiatives and peer support groups often play a key role in supporting individuals who do not seek medical help through the NHS.

Some respondents from boards without GICs who did not feel able to answer this question noted that this was because they received little feedback from specialist services on who had been referred for treatment, whether these referrals had been accepted, or how those living in their board utilise the pathway. There was a feeling expressed that these boards would be keen to have more awareness of these factors

so that they are able to link individuals in to any local services while they are waiting for GIC assessment.

### **Has demand for services been increasing in your area?**

All interviewees agreed that demand is increasing and several commented they felt it had been increasing markedly every year for the last few years, with more than one describing it as feeling 'exponential'. This increase in demand was described as covering demand for health services from trans individuals, and demand on community organisations for support, in addition to an increase in enquiries to and from professionals outside of the health service, e.g. teachers asking for support on how to approach trans issues. The change was noted to have occurred across the entire lifespan: children and families, adults, older adults etc, though there was definitely noted to be an element of earlier presentation of trans individuals at a younger age.

### **If yes, why do you think this might be happening?**

A range of potential explanations for the increase in demand was given. Many of the same explanations were offered by a number of interviewees, indicating consistency of ideas amongst the people interviewed. These explanations have been grouped into themes below.

#### **Service Provision Factors:**

Increased awareness and accessibility of the GRP and services which go alongside it, including awareness of what interventions can achieve in terms of gender transition; fewer barriers to accessing services; small numbers of staff at GICs mean services are not resilient to unplanned absences; services are less restrictive with an improved understanding of the need for an individual or 'some but not all' approach to interventions, encouraging more non-binary people to access services; increased access to community support, especially for young people in schools/universities.

#### **Societal Changes:**

Increased public awareness and acceptance of trans people, allowing them greater social inclusion; cultural barriers are decreasing; greater visibility of trans people; less stigma; people are more willing to reject gender norms and have a more flexible understanding of gender; having a positive gay rights agenda has demonstrated the possibilities for trans people's rights, particularly visibility and growth of LGBTQ+ groups, Pride etc. in local areas.

#### **Changes amongst the Trans Population:**

People have greater personal recognition of being trans due to increased visibility i.e. individuals have 'found words for themselves'; young people understand gender differently; trans people feel more empowered; the prospect of transition and what it can consist of is more tangible than for previous generations.

**Media:**

Greater Internet access means easier access to information and online support from other trans people around the world; the cultural shift to social media from mainstream media, where trans people can be more visible; presence of more high profile trans people and trans role models (although there are fewer high profile trans men).

**Greater Legal Protections:**

There appears to have been surprise in the trans community at all the changes that have taken place and that are continuing to happen e.g. Equality Act, Gender Recognition Act, employment rights. These positive changes mean that trans people may no longer feel that they will lose everything if they come out, whereas in the past they could have feared losing their job, family, house etc. It was also discussed that there has been a shift in education towards teaching equality and diversity and children's rights in schools, therefore more young people are aware that they have these rights, and the right to their own identity.

**Do longer waiting times have a detrimental impact on your patients?**

Interviewees universally agreed that long waiting times following what has already potentially been a long period coming to terms your identity and seeking treatment can cause frustration and irritation for patients, and have detrimental effects on physical and mental health. For young people the wait can be an issue if it delays starting hormone treatment whilst they are going through puberty, causing extreme distress for them and their families. Similarly for older teenagers and adults who experience severe dysphoria the wait for assessment and access to treatment can be equally difficult, impacting on mental health and potentially driving individuals to seek hormones etc from other sources. Several respondents described that, from their experience, they believed this period when individuals are 'stuck in limbo' with their lives on hold is a point when trans people are more likely to experience high levels of distress and/or suicidal ideation and self-harm.

It was expressed by interviewees from all areas that the period while waiting can be made more difficult due to the lack of information or support available, and that it could be better if people were seen sooner through local services. There is also scope for better signposting to third sector initiatives and peer support groups, which can play a key role in providing support and information to individuals whilst on the GIC waiting list. This signposting could allow some care to begin before the specialist assessment happens, and the detrimental impact could be lessened if there was social and other support available e.g. counselling, but this is not provided by most NHS services at present. Interviewees from boards with no local services expressed frustration that they do not currently have anything to offer to these individuals, and that they would have difficulty doing so even if they did as they do not know who is on the waiting list.

It was also noted that the long wait could have a negative effect on the clinician-patient relationship. There was noted to be increasing pressure from the trans community around the rationale for why GICs are not governed by waiting time targets, and for

GPs to be able to prescribe hormones given how long the wait is to be seen at a GIC before starting treatment.

### **Are there any barriers or bottlenecks for patients moving along the care pathway?**

A range of potential bottlenecks in the patient journey through gender services were identified:

- Delay in presentation
- Initial waiting list
- Waiting time for second opinion at another GIC (if required)
- Waiting time for surgery
- Other referral points, e.g. for medical assessments, hormone assessments, counselling, or endocrinology, once in the system.

These delays are cumulative, and all interact to extend the patient journey. Whilst these additional waiting times were seen as highly detrimental by most respondents, a small number of respondents felt that in a minority of cases having time between appointments could be advantageous, as patients may change their minds about the treatments that they would like to receive. Several examples of more specific barriers were highlighted by interviewees including: inconsistent access to and funding for hair removal services in different health boards; delays in accessing treatment due to BMI; UK-wide delays in accessing phalloplasty; delays in accessing breast augmentation at some centres; delays in accessing fertility services due to Scotland-wide issues with gamete storage; and inconsistency in GP willingness to prescribe e.g. minipill to induce amenorrhoea for trans men.

Interviewees highlighted that the majority of these bottlenecks occur because demand is exceeding capacity, and some related this to workforce and recruitment issues in gender identity services. Additionally it was suggested that self-referral can mean that clinicians do not know much about patients at their initial appointment, which can cause an additional extension.

### **Do you think there are potential sources of inequalities in access to gender identity services in your area?**

The majority of respondents to this question felt that there were potential inequalities in access to gender identity services, and identified a range of potential factors that could make it more difficult for individuals. It was highlighted that many of the factors which could limit access to health services in general would also affect gender identity services.

#### **Geographical Factors:**

Rurality e.g. living in a rural area may make it more challenging for someone to come out as trans both due to perceived stigma and lack of confidentiality in small communities; travel issues, including that travel can be difficult for young people, it can be a daunting prospect whilst transitioning, there may be poor availability of public

transport, and travel/time costs (travel from islands to attend a half hour appointment takes 3 days); unavailability of a local service in boards without a GIC; requirement to take considerable time off work to attend appointments which could inadvertently 'out' people; lack of ability to teleconference/videoconference to attend appointments for those in very rural settings. It was highlighted that people may choose to move to big cities, such as Glasgow or Edinburgh, for services and community, though it was felt by some respondents that this is happening less as societal attitudes improve, and so more local services will be required.

### **Co-morbidities:**

There was concern that people with mental health issues, learning disabilities, and autism spectrum disorders may have difficulty accessing services, either due to their condition or the perception that these require to be dealt with prior to gender identity issues; those with poor literacy may have issues finding or accessing information about services and treatment.

### **Ethnicity and Migration:**

A number of interviewees highlighted a concern with whether people from Black and Minority Ethnic (BME) groups and refugees and asylum seekers had difficulty accessing gender services, with some mentioning work in England that has found BME people may be less likely to access services; also ethnicity may affect the outcomes of treatment such as hair removal, but the same number of sessions are offered to all regardless of result, potentially disadvantaging those from certain ethnic groups.

### **Language:**

It was noted that few individuals needing interpreters were seen, and there was concern that literacy issues or being a British Sign Language user may make it difficult to access services.

### **Socioeconomic Deprivation / Financial:**

Travel for GIC assessment or to England for surgery could present a barrier; people may not be aware that treatment is available on the NHS.

### **Older People:**

May be less likely to be online and have access to information about trans services.

### **Physical Disabilities:**

These could make it difficult to physically access services, particularly where it involves extensive travel; also those requiring physical care are constantly required to 'out' themselves to medical and care staff in other services.

### **Young People:**

Attending a gender clinic in a sexual health clinic may be difficult for young people and their parents; young people are likely to require family support to be able to attend appointments, especially if they need to travel as from some areas of Scotland this

takes several days; often young people are unable to attend appointments without letting family know if they are not supportive, as schools will inform parents of an unplanned absence.

### **Gender Identity:**

Non-binary people may be less likely to access services due to their perception and the reality that treatment pathways are geared towards a binary model.

### **Cultural Attitudes:**

Trans people can be directly or indirectly discriminated against in accessing other NHS services, such as gendered CHI numbers causing issues accessing screening, being required to register with many services as only male or female, and some GPs or other healthcare workers being unsupportive.

### **Other:**

One respondent mentioned that there is probably under-provision of services for trans people in the prison system; another respondent discussed that not accepting self-referrals limits access to those with unsupportive GPs or those who have not registered with a GP practice either due to chaotic lives or the very gendered registration process.

### **Has the type of patients you have been seeing changed?**

Interviewees from clinical and voluntary organisations identified increases in demand from a range of groups of patients, although the groups varied between interviewees. Groups identified included:

- More non-binary individuals\*
- Younger adults, e.g. under 25 year olds, whereas in the past more people in their 30-40s were being seen
- More older people in 50-60s who previously may not have come forward
- More pre-pubertal children
- More trans men, especially in the younger age groups
- More people who self-describe as exploring or questioning their gender identity rather than definitively seeking treatment options
- More people with complex presentations or autism spectrum disorders.

*\*Some interviewees wondered whether actually non-binary individuals now just felt more confident to openly express this without fear of being denied certain treatments.*

### **What is the current approach to people moving on or being discharged from specialist gender identity services in your area?**

Patients may be involved with GICs for a number of years, and it was noted that the specialist services do not tend to discharge people, although GPs may be asked to continue long-term follow-up of hormone treatments. Rather, a patient-centred or open-ended approach is taken so people can continue to be seen if they want to. This

contrasts with local services which, where they exist, tend to provide care only until the point where specialist services take over and/or a specific treatment episode ends.

### **How often are you aware of patients using services outside the NHS to support their care, including third sector, UK private and international private provision?**

Most interviewees were aware of patients accessing third sector or community resources, and several actively signposted patients to such services. Demand for such services has increased in parallel with that for GIC appointments, and this growth has exceeded the projections put together when services were set up. It was described by several respondents that community support groups were often 'grassroots' i.e. set up by lay volunteers to fill a recognised need. An example given of this was a support group for parents of young trans people in a remote and rural area, which was established by parents who felt that would have been useful to them in the past. It was discussed that voluntary sector and informal community support is not universally available, with groups for young people prolific at school and university, but third sector provision for adults largely focused in Glasgow and Edinburgh with gaps in services elsewhere.

In relation to private provision of gender services, interviewees largely responded that they felt this was rare due to the prohibitive cost, particularly for surgical interventions, though there were reports of small numbers of individuals accessing private counselling or hormone prescription. More common was for people to access hormones from other sources, usually either from other trans people or online. One interviewee reported that anecdotally while this used to be relatively rare in Scotland in comparison to other countries, they perceive that there has been an increase recently due to easier access and a rising number of people on waiting lists who have already socially transitioned at an early age and 'need their body to catch up'. There is a clear risk to this, particularly as individuals may not disclose that they are self-medicating to GICs and stop taking the hormones before getting their bloods checked. One respondent felt that parents of trans children were potentially more likely to pursue private treatment while waiting for assessment, as they can be under extreme pressure due to the severe distress experienced by their children at puberty when intervention is time-critical and self-harm/suicidal ideation is common. Most interviewees reported that they were aware of trans people accessing additional private hair removal outwith what is available on the NHS, sometimes from colleges where this is less expensive.

### **What do you expect to happen to demand in the future?**

A range of suggestions as to what may happen to demand in the future were offered. Most interviewees felt that demand was likely to further increase to a plateau, though views on when this might occur were varied. Most interviewees did not perceive a slowing in demand yet, though it was felt by some respondents that the biggest increase may have already happened when people began to have access to the terminology and information online to self-identify. Several respondents felt that it is likely the eventual plateau in demand will represent the true underlying need where,

as services have become more accessible and society has become more accepting, all trans people feel able to access the services they need.

It was felt that there were likely to be continuing increases in the numbers of non-binary people and younger trans people presenting, as well as potentially a continual shift until equal numbers of trans men and trans women are presenting. Further increases in the number of young people presenting could occur if other services, such as education, responded better to trans young people. It was highlighted that demand for adult services is likely to increase in future as the higher number of young people being seen move onto adult services.

Trans people who present to services may also make a greater range of requests for interventions, requiring a more tailored approach to treatment. In relation to surgery, one respondent reported that there have been shifts of opinion within the trans community in the last few years for varying reasons which may result in an increased number of requests for masculinising genital surgeries, and a decreased number for feminising genital surgeries in future.

It was also highlighted that, if society changes over time to the extent that gender is seen as less of an issue with trans identities being normalised, this could reduce demand for specialist gender services. However, no-one felt demand was likely to decrease in the near future, except for some aspects of services that would be less relevant if there was increased early intervention e.g. demand for SALT is likely to be reduced by use of hormone blocking in young people.

### **What do you think could be done to address changes in demand?**

Interviewees suggested a range of potential ways to deal with increased demand for gender identity services, some of which built on existing structures and some of which suggested significant change:

#### **Workforce Development**

e.g. dissemination of knowledge and skills through Continuing Professional Development and training for other services such as primary care and CAMHS; also, to help develop a specialist workforce.

#### **Increased Capacity**

e.g. more staff and resources, including nursing staff, at GICs; increased accommodation so that more patients can be seen and more trainees taken on; workforce development in boards which don't yet have a GIC to improve local provision and ease pressure on central services.

#### **Young Person's Service to Work More Closely with CAMHS and Others**

e.g. to provide telephone support; make more use of CAMHS services for young people with other mental health issues; CAMHS patients to have an initial assessment there before coming to gender identity service; link in with educational psychologist

network, a valuable resource that could increase schools training such that referrals for specialist care actually decrease.

### **Changes to Assessment Pathway**

e.g. pre-assessment questionnaires to speed up assessment and allow earlier signposting to other services; triage referrals and refer to most appropriate person based on needs; prioritise time-critical referrals such as distressed pubertal young people.

### **Changes to Service Provision**

e.g. provide service/space at GIC for those questioning gender identity such as individual or group counselling, rather than focusing appointments on assessment, to avoid individuals progressing down a medicalised pathway that may not be right for them; design adaptable adult services which are responsive to changes in how the population presents (such as the decrease that will hopefully occur in post-puberty issues with provision of YP clinic); increase multi-disciplinary working to free senior staff time for the most complex patients, rather than them being required to review all referrals.

### **Alternative Service Models**

e.g. decentralising services and making them more community facing; create a network model with development of local skills and support, with pre-GIC services as exist in NHS Tayside at present; development of more nurse-led services to aid in capacity building, particularly in boards without a GIC; outsourcing of information, support, and counselling services to third sector to build capacity and enable people to explore their goals, fears and perceptions of transition separate from the NHS and the process of assessment for treatment. Further similar suggestions included working more with local services, e.g. education and social services, to develop their support skills, and develop a better shared response from the range of services available. However, it was also expressed by some interviewees that they felt the issue was one of capacity rather than needing a change in practice.

### **Are you anticipating or planning any changes in gender identity services in your area?**

In boards with a GIC there were no plans to significantly change the way services were structured other than slight changes to staffing. In those without a GIC there were variable plans, including trying to increase provision of local trans-specific services and increased workforce equality and diversity training. However, interviewees acknowledged that in the current financial climate it is challenging to introduce new services and that wider support would be required for significant changes to be made to services. It was also felt that setting up local services is difficult as there is a lack of expertise in the local workforce, and any progress would be likely to require linking with an existing GIC in the first instance. It was noted that at present there is a move across the NHS in Scotland towards more regional working, so this may have an as yet unknown impact on gender identity services.

Interviewees from some third sector organisations noted that they would be keen to expand their service provision and link more with NHS services to reduce pressures, but that this would be dependent on being adequately funded to do so.

### **Are any changes needed to the way gender identity services across Scotland work together?**

A range of issues with the current service arrangements were highlighted, some centred on workforce capacity, particularly the loss of the Grampian service for an extended period of time. It was felt that limited capacity and the current structure of GICs meant patients did not have sufficient time to explore all of their issues and express any doubts they are having, fearing further waiting times if they do so. Further, there was concern that patients may just say what they think they need to in order to get treatment, e.g. hormones. More generally, there was concern that people are presenting to voluntary services with severe mental health issues, including suicidal ideation, because of difficulties accessing gender services or community mental health services. It was suggested that a way of overcoming some of these issues would be to provide both additional support during waiting times and some form of process for people to explore their goals, fears, and perceptions of transition, in an environment that is separate from the process of assessment for treatment.

There was some discussion around expansion of the workforce and de-specialisation, particularly with the plans to move the categorisation of gender identity disorder in ICD-11, with suggestions raised that it may no longer be necessary for services to be run by psychiatry. Alternative suggestions were for the service to be owned by sexual health or to be entirely multi-disciplinary, with each carrying positives and negatives. There was clear support for more services to be provided locally for both adults and young people, though the degree to which it was suggested this would replace or complement the existing model varied between respondents. Respondents from one board described that they have a commitment to achieving accessible services for patients within 50 miles or 30 minutes travel time, and that this is currently far from achieved for gender identity services. The possibility of satellite or virtual clinics was suggested as a novel solution to geographical inequalities, particularly for the Sandyford YP service where the only centre for appointments is Glasgow. There was universal support from boards without GICs for increased communication about which of their patients were on the waiting list/being seen, to enable them to assist with relieving service pressures and provide appropriate local support.

It was discussed by both healthcare professionals and those within the third sector that links between voluntary services and specialist gender clinics need to improve. For example, the GRP specifies that access to counselling should be provided but this is not always the case, and while the voluntary sector are able to provide this they are not always adequately funded to do so. Improving these links and providing greater support for community services was felt to have the potential to reduce demand for specialist services.

One respondent suggested a possible improvement could be that referrals for other gender identity related procedures could be processed nationally in the way that chest/genital surgeries currently are, including hair removal and facial feminisation surgery, to reduce variability in access by board.

There were positive comments from several interviewees about the existence of the National Gender Identity Clinical Network for Scotland (NGICNS), and the improvements this has led to in availability of data on referral numbers and waiting times. It was also described as supporting a holistic and collaborative approach which acknowledges the need to work with third sector organisations, which was felt to be helpful. One suggestion from a respondent for future work of the NGICNS would be in setting a national standard for what is expected from a GIC, as the existing clinics have grown organically and are therefore fairly different from each other with no real benchmark standard, making it challenging for any health board to contemplate starting one.

There was a feeling expressed by many respondents that it is difficult to know the ideal situation until we know where referral numbers are likely to stop, but currently GICs are overwhelmed, therefore there may be a need to make fairly radical changes to the way services are delivered. One respondent felt that provision was likely go in one of two directions: more structured GIC provision with expansion of current GICs and creation of more, or mainstreaming of trans/gender identity services including hormone provision, with little seen as specialist about it.

#### **Do you collect any data on user satisfaction?**

Few respondents from NHS services reporting collecting data on service user satisfaction with services and outcomes. Third sector organisations reported that in contrast they do considerable amounts of evaluative work, largely because their funding is often dependent on this, and often use reflective modelling to assess what parts of the services offered those using them would like to see change. There was a view from respondents that collecting these data for GICs would be useful and informative, and an openness to considering doing so in future.

#### **Do you have any other comments?**

Finally, interviewees were asked whether there were any other issues that they would like to raise. In particular, the lack of surgical provision for gender reassignment surgery in Scotland was highlighted, including a lack of local support for dealing with surgical complications. This issue was felt to be increasingly pertinent given the potential for rising demand for surgery in the future. There was support from several respondents for the idea of improving data collection at GICs so that there is a clear prospective dataset of trans patients created, which could be used to monitor referral rates, waiting times, and outcomes. One respondent highlighted that the need to access GICs by phone rather than email could be an additional barrier to trans people who are particularly self-conscious about their voice (which is common), and so having online or email access to all GICs would be helpful.

Some interviewees discussed the Gender Reassignment Protocol (GRP) itself and whether this was still fit for purpose in its current form. It was felt that the GRP was a product of the time in which it was written, and as a result was not as inclusive of non-binary individuals or a person-centred approach as it may be had it been written now. There was a feeling that, while not a service priority, it would be useful for the GRP to be updated in terms of language and shape, to make it clear that non-binary outcomes and less 'typical' treatment plans are just as valid as the clear binary pathways shown in the current flowchart.

## Summary

These interviews allowed the views of a variety of gender specialist staff, other professionals, and people working for specialist transgender organisations to be elicited on the questions described. It was felt that there was a wide enough degree of coverage of both different areas and different professions to give a reasonably representative national overview. There was a great deal of consensus in the responses to the questions asked on demand and potential sources of inequalities, with no marked disagreement in views noted between the people interviewed. However, there were differences in opinion on what the appropriate response to this increasing demand should be, with those involved with established GICs generally feeling that preservation of the existing model with increased capacity would be sufficient, and those from other areas feeling that more significant change may be required.

The findings of these interviews indicate that demand for gender identity services is increasing, and the types of individuals presenting to services is changing with more non-binary individuals, younger people and trans men presenting. These changes may be happening for multiple reasons including greater service provision, societal changes, and greater access to information on transgender issues through the Internet and social media. There are issues arising from demand for services exceeding current capacity in both the NHS and the third sector, including long waiting times and bottlenecks in the care pathway. There may be some population groups that have difficulty accessing gender identity services, some for reasons that are specific to gender identity issues and others for reasons that may apply to other health services. A range of suggestions on how services could adapt to address these changes in demand were made, including increasing capacity further, providing more education for health professionals, and considering alternative service models, in particular those that would create better links with community and primary care services.

## What Does This Mean For Us?

Though there was little evidence in the scientific literature about projections or changes in the trans population presenting to services, specialists and stakeholders working closely with trans communities clearly describe an increase in demand from young and non-binary people. Many possible explanations were suggested, but the most important consideration going forward is how to ensure services are designed to meet the needs of the population presenting now.

While views of service providers are important in guiding any changes to services required, the views of service users (particularly these groups who may have had less of a voice when services originated) are essential. This might be especially helpful in this case, where experts differ in their views on how to improve things. Consultation and collaboration with the trans community on potential options will be needed to make sure all trans people feel their needs are met by services, and inequalities are reduced as far as possible.

### Service User Views

There were 255 respondents to the Scottish Trans Alliance (STA) survey, which based on the service usage data crudely represents approximately 21.1% of the patient population who had attended clinics over the three years asked about (2014-2016). This is likely to be an overestimate of response rate as referral numbers during this time period were not received from Grampian GIC. While there are limitations in interpretation of these data due to this relatively small response rate, the provision of anonymity and administration by a third sector organisation rather than health professionals resulted in disclosures which may not have achieved through other means.

The representation of trans men and trans women among survey respondents was similar: 39% reported a constant and clear gender identity as a man, while 38% reported a constant and clear gender identity as a woman. 38 respondents, 15% of the sample, reported a non-binary gender identity. 53% of respondents were aged 24 or under, 36% were aged 25-44, 10% were aged 45-64 and 1% were aged 65 and over. 60% of respondents were answering about the Sandyford Adult GIC, 20% about the Chalmers Centre in Edinburgh, 11% about the Sandyford Children and Young Person's Service, 7% about the Grampian GIC and 2% about the Highland GIC.

### Waiting Times

The prevailing theme of survey responses was dissatisfaction with waiting times to access services. Only 12% of respondents had a first appointment within six months of referral, and 5% of patients waited over 18 months. 39% of respondents who answered a free-text question at the end of the questionnaire expressed concerns about the length of wait for a first appointment and the perceived consequences of this, with 6% suggesting that there should be increased contact from GICs to those

waiting to keep them informed and potentially signpost them to other services while they wait (n=83). 67% of respondents reported having poorer mental health, 62% lower self-esteem, and 58% feeling more isolated or excluded due to the time they waited for a first appointment (n=251). Concerningly, 29% of this group reported self-harming and 13% attempted suicide or engaged in drug or alcohol abuse due to the waiting times.

### Box 2: Excerpts from Respondents - Waiting Times

*“I think the long waiting list has been extremely detrimental to my mental and physical health because there's nothing that my GP or psychologist can do to ease the process, it just hurts.”*

*“The waiting times are an absolute disgrace and place people's lives at risk.”*

*“The waiting list process is incredibly cruel with a huge impact on trans peoples' health, the most significant thing to me was I received no contact whatsoever from the clinic, I was completely unaware of my position on the list or of absolutely any third party support available while I waited.”*

### Gender Reassignment Protocol

57% of respondents had been aware of the national gender reassignment protocol before their first appointment at a GIC. However, 67% of respondents who had had an appointment at a GIC had not been made aware of the protocol by someone at the clinic (n=115). While a majority of respondents found the information in the GRP accessible, 18% found it inaccessible or very inaccessible.

Of those who had attended a GIC, 30% of respondents felt their experience differed from the protocol, 33% felt that it had not been different, and the remaining 37% were unsure (n=111). A theme which emerged from further comments by those who perceived a difference between their treatment and the protocol was a perceived lack of explanation given for delays or difficulties accessing treatment.

Respondents were asked for suggested changes or improvements which could be made to the protocol, and there were 39 responses. The three main suggestions were that the protocol should be followed and that all services should be aware of it; that the protocol should be more inclusive of those with non-binary gender identities; and that there should be a move to an informed consent model with reduced gatekeeping around gender identity or expression. One respondent also suggested that it could be helpful to have a printed version of the protocol available in clinic waiting rooms to increase awareness.

### Box 3: Excerpts from Respondents - Gender Reassignment Protocol

*“[The protocol] seems to strongly favour those identifying with a binary gender... and especially those who seek to identify entirely as the opposite of their gender assigned at birth. To me the protocol could be, perhaps unintentionally, harming non-binary or genderqueer patients.”*

*“The most accessible part of the protocol is the flowchart but it seems to focus majorly on genital surgery, when the desire or lack thereof for certain surgeries differs for every single person.”*

*“[I’d suggest] much less focus on presentation, move to informed consent - clinicians should simply explain what various medical interventions do and how they are likely to affect your body/emotional state.”*

### Experience of GICs

Positively, 77% of all respondents who had attended an appointment agreed or strongly agreed that clinicians had listened to them during appointments (n=186), and 70% agreed or strongly agreed that they felt able to ask clinicians questions. However, non-binary individuals reported more negative experiences with clinicians: 24% of this group disagreed or strongly disagreed that they felt listened to during appointments, compared with 11% of those with a binary gender identity. 70% of respondents wished to see the same clinician at all appointments, but only 55% did (n=168).

A key theme which emerged from the data was lack of disclosure or withholding of information by individuals at clinic, closely linked with a perception of pressure to behave in a certain way to access treatment. 30% of respondents reported either withholding information or lying to a clinician at a GIC about something to do with their gender, and 30% reported feeling pressurised to do something they did not want to do (n=186). Participants were invited to give examples of such occasions, some of which are illustrated in Box 4.

Recurring points were a perceived need to present and dress in a stereotypical way in order for their gender identity to be accepted, even where this did not fit with their preferences; a pressure to report that they had entirely socially transitioned even where this was not yet possible in all settings; and a perceived need to withhold information on sexual identity or mental health issues where individuals felt this could create barriers to treatment.

#### Box 4: Excerpts from Respondents – Withholding Information & Pressure to Conform

*“I withheld my pansexuality, as I had heard many others using GIC services had hit barriers to treatment when not fitting in a neat box of straight or gay.”*

*“Lied and withheld information about my mental health, gender identity, gender presentation, sexuality, childhood, family rejection, friend rejection, certainty about my gender, certainty about my medical transition, how I was feeling, what I was thinking. Pretty much most things.”*

*“[I withheld that] I was only full time 75% of my first year. Most family and friends wouldn’t allow me to enter their home unless I dressed as male.”*

*“[I] wore others clothes, [as] I was told directly that my dress sense was the reason for my dysphoria and as such did not need hormones. Both impacted my mental health for weeks after.”*

*“Presenting any elements of my story which were atypical to the accepted narrative may well have resulted in not being able to access treatment.”*

Overall, 56% of respondents who had experienced uncertainty about their gender while attending a GIC (n=55), and 54% of those who felt emotionally distressed or worried about their mental health (n=136), had felt unable to talk to clinicians about it. When expanding on this, respondents frequently mentioned a fear of prolonging delays to their desired treatment if they were honest about either their gender identity or their mental health, illustrated in Box 5.

#### Box 5: Excerpts from Respondents - Expressing Gender Identity & Mental Health

*“I have always felt I was non-binary but having heard past experiences of non-binary people not being allowed access to hormones or surgeries I felt I wasn’t able to mention this. This was due to fear of being denied the hormones and surgery I needed to have to live without dysphoria and live comfortably as myself.”*

*“The gender specialist I had appointments with made me feel like if I had any doubts, I was not going to be taken seriously as a trans person.”*

*“So many people are held back from getting hormones or surgery due to poor mental health. This makes you feel like you can’t speak about anything negative in your life because the appointments are so far apart any delays will just cause worse mental health problems.”*

*“I felt that if I brought up my poor mental health and my mental illnesses, they’d use that as a way to deny me treatment... I feel like the current system is quite ableist, assuming that mentally ill people are just too “crazy” to decide such things for themselves.”*

In relation to the current organisation of GICs in Scotland, 60% of respondents felt that the wait between appointments was too long (n=151), and 20% felt that the distance and time it took them to travel to clinic was not acceptable (n=167). Due to small numbers, these data were not broken down by the site of each GIC. 21% of respondents felt that, since attending a GIC, their ability to access other NHS services had been reduced (n=117). Where individuals felt they had issues in accessing services and left further comments, these predominantly centred around a perception from other services that all related care (e.g. sexual health, mental health) was now taken on by the GIC, rather than solely issues associated with transition. Only 42% of respondents felt that clinicians at GICs had signposted them to additional support services, with 38% feeling that they had not been signposted appropriately (n=184).

### **Experience of Treatment**

By the time of their first appointment at a GIC, 88% of respondents strongly agreed or agreed that they had already decided on whether or not they wished to take hormones (n=184), and 76% had already decided whether or not they wanted to have any surgeries (n=186). However, of those who were subsequently prescribed hormone treatment, 47% waited more than six months from their first appointment for this (n=129).

### **Hormone Treatment**

A majority of individuals, 67%, felt that clinicians adequately explained the different hormone options to them prior to beginning treatment, though 23% of respondents felt that clinicians had not taken into account their personal needs and preferences (n=147).

In terms of potential side effects of hormone treatment, 73% felt that they had been given clear information on the risks of hormones prior to treatment – in the associated free comment sections some individuals commented that while the risks were explained there was less information on how such risks could be managed (n=148). A majority of respondents (64%) reported being given information on how hormone treatment could impact their future fertility, however the main theme of related additional comments was a lack of discussion around options of preserving fertility prior to beginning treatment (n=148).

Where hormone prescription was requested from a General Practitioner by the GIC, 11% of individuals identified that this prescription and monitoring did not progress smoothly (n=109). Overall, individuals taking hormones were highly satisfied with their experience of the treatment: on a scale of 1 to 7 with 1 representing 'very dissatisfied' and 7 representing 'very satisfied', 90% of respondents scored their experience between 5 and 7, with 50% scoring 7 (n=97). A selection of representative comments covering feedback on hormone treatment are shown in Box 6.

### Box 6: Excerpts from Respondents - Hormone Treatment

*“Options were not really discussed. It was basically this is what we prescribe. However, effects were discussed in appropriate detail.”*

*“I wasn't asked which hormone type I would prefer I was just told that I would be started on a particular type of testosterone. Fortunately this was the one the best fit my lifestyle needs and preferences but I was not at any point asked if this was the case.”*

*“The dosage I was given was tailored towards my non-binary and androgyne gender. This helped me feel validated as an individual and gave the impression that [the GIC] was keen on resolving my gender dysphoria foremost.”*

*“I was never given any options or info about storing eggs. This is something I would have done to use with a surrogate but didn't know until it was too late.”*

*“[Hormones] should be supplied without delay on an informed consent basis.”*

### Chest/Breast Surgery

Of respondents who had discussed chest/breast surgery at a GIC, 46% of individuals felt that the clinicians had explained the different options available to them, while 36% did not, with the remaining individuals unsure (n=96). Additionally, 54% of respondents felt that clinicians had then taken account of their personal needs and preferences, while 26% did not (n=95). These results were broken down by the type of chest/breast surgery requested, and there was no statistically significant relationship between specific types of surgery and response to either question. There was no clear reason identified for the diverse responses to these questions, and additional comments provided describing consultations (illustrated in Box 7) were similarly varied.

### Box 7: Excerpts from Respondents - Chest/Breast Surgery

*“[The clinician] said it's possible a referral will be put in before the usual time after taking hormones for top surgery due to my pain condition that prevents me from binding.”*

*“It was all about what they thought and less about my thoughts and feelings.”*

*“I explained to the clinician that I would be unable to have surgery in spring or summer due to the nature of my work... [They were] very understanding about this and said that my demands were realistic.”*

*“Seemed to be all about what suited NHS system rather than what was right for me!”*

Of those individuals who had completed chest/breast surgery, 85% felt that their personal needs and preferences had been taken into account by their surgical team, 100% felt they had been given clear information on risks of surgery, and 92% felt they

had been given clear information on possible surgical outcomes (n=13). Just over half of the same respondents had their travel expenses covered by their NHS board, and the remainder did not request these. Overall satisfaction with chest/breast surgery was high, with 83% of individuals scoring it as either six or seven on a seven-point scale.

### **Genital Surgery**

As with chest/breast surgery, there are many options available to trans individuals for genital surgery. While all genital surgical procedures are provided in England, referrals are made from Scottish GICs and so respondents were asked whether they had ever discussed genital surgery options at a GIC. Of those who had, 48% felt that clinicians explained the different options to them, while 28% did not, with the remaining individuals unsure (n=87). Similarly, 59% of the same respondents felt that clinicians took account of their personal needs and preferences when discussing options for genital surgery, 20% did not feel these were taken into account. Again, additional comments left to these two questions illustrated a similarly mixed set of experiences for trans individuals attempting to access genital surgery.

#### **Box 8: Excerpts from Respondents - Genital Surgery**

*“They had their own idea of when and how it should take place, and any thoughts outside of this were quickly and politely put to rest.”*

*“I talked about the possibility of orchidectomy and they just said bluntly, “No.” When I asked about how GRS works they gave me vague answers so I had to do research online.”*

*“I was nervous that when I requested an orchidectomy that they'd just turn me away, but I was very happy when I was told that the NHS would fund [it].”*

*“Only one option was presented so personal needs and preferences were rendered irrelevant.”*

*“They were fine with me saying that I wanted genital surgery, but wasn't sure what option to take yet, and would decide in the future.”*

Of those individuals who had completed genital surgery, 80% of felt that their personal needs and preferences had been taken into account by their surgical team, 87% felt they had been given clear information on risks of surgery (n=15), and 93% felt they had been given clear information on possible surgical outcomes (n=14). Overall satisfaction with genital surgery was again high, with 91% of respondents scoring it as either five or seven on a seven-point scale; the remaining 9% rated it slightly negatively (n=11).

## Other Interventions

Experiences of hair removal and speech therapy were also included in the GIC survey, though some of these services are likely to have been provided in the NHS board where the individual resided even where this differed from their GIC.

Of respondents who had discussed hair removal at a GIC, 59% felt that clinicians had explained the different options available to them (n=68), while 26% felt that their personal needs and preferences were not taken into account (n=69). Additional comments provided indicated that where options were not fully explained this was often because clinicians said that only one was available and so did not explain alternatives. The amount of time individuals waited from first appointment to receiving an appointment for hair removal and the number of sessions funded was extremely varied, and was shown to differ in relation to health board, however possibly due to small numbers there was no evidence of a statistically significant relationship.

82% of those who underwent treatment had received funding for the areas of their face and body that they wanted (n=51), 74% received funding for the type of hair removal they wanted (n=50), and 63% received funding for the amount of hair removal sessions that they wanted (n=49). When these results were organised by health board and numbers less than five excluded, NHS Grampian had the highest level of satisfaction with hair removal funding, NHS Tayside and NHS Greater Glasgow and Clyde were around the average, and NHS Lothian had the lowest level of satisfaction, though no associations were statistically significant. Satisfaction with hair removal was reasonably high but lower than for hormone treatment or surgical intervention: 71% scored their satisfaction between five and seven on a seven-point scale, with 23% scoring it from one to three (n=34).

### Box 9: Excerpts from Respondents - Hair Removal

*“Hair removal has really helped me with my self-esteem and mental health, I would say to the same degree as taking hormones.”*

*“The laser hair removal helped but was not as effective as I had hoped, and there does not appear to be funding available for further sessions.”*

*“The costs of having to top up every six months privately can be exhausting financially but I understand the NHS isn't a bottomless pit.”*

Of respondents who had discussed speech and language therapy (SALT) at a GIC, 43% felt that clinicians had explained the different options available to them, and 57% felt that their personal needs and preferences were taken into account (n=67). As with hair removal, the amount of time respondents waited from their first appointment at a GIC to accessing SALT varied, with 23% of respondents receiving an appointment in under three months, a further 13% beginning within six months, and 23% of

respondents waiting over a year. When compared with attendees at other GICs in the UK, those attending Scottish GICs were shown to have a shorter wait for access to SALT: 35% of respondents had accessed SALT by six months, compared to 17% of respondents at all other UK GICs (n=239), and this difference was statistically significant. Similarly to hair removal, satisfaction with SALT was overall high but lower than hormones and surgery: 65% of respondents rated it between five and seven, with 21% of respondents rating it from one to three (n=34).

#### Box 10: Excerpt from Respondents - Speech and Language Therapy

*“The therapist I see is very good. [They have] very little experience with non-binary people but [are] very accepting and adaptable.”*

*“The therapy was excellent but I had to stop attending because I felt under pressure to dress female.”*

*“The speech therapist told me that I was too feminine and that I spoke too much like a girl and that she couldn't help me.”*

*“My voice therapist was lovely and it definitely gave me useful information on changing my voice, although I didn't get that many sessions, but it has definitely helped.”*

#### Self-Funding Treatment

The proportion of those who attended Scottish GICs who had ever accessed self-funded private transition treatments was 25% (n=187), markedly lower than the results of the same survey for attendees at all other UK GICs which found 49% had accessed such treatments (n=540). Those attending Scottish GICs were also less likely to have accessed hormone treatments from non-NHS sources than their UK counterparts, with 9% reporting having obtained a private prescription (n=166), 11% having bought hormones online (n=169), and 8% having received hormones from a friend (n=166), compared with 25%, 25% and 16% respectively (n=480-498).

#### Summary

These data summarise the views of a fairly representative sample of trans service users who accessed GICs in Scotland between 2014 and 2016. The main concerns expressed were around long waiting times to access services and the distress this caused, and a perceived need to withhold information on gender identity, mental health, and gender expression for fear that this would block or delay access to treatment. There was also reporting across several types of treatment of lack of explanation of the different options available by GICs, with a view expressed that this reduced agency and personal preference of the individual. Those with non-binary gender identities were more likely to have had negative experiences with GICs, and there was a feeling that the current GRP was not inclusive of non-binary individuals or

supportive of an informed consent model. However, overall experience of treatment outcomes was largely positive, particularly for hormone treatment and surgery, and there were some very positive experiences of person-centred care described.

### What Does This Mean For Us?

Trans people accessing gender identity services in Scotland have a number of concerns about the way they are structured, despite finding that their experience of individual treatments was often good. It is key going forward that all trans people accessing services, particularly those with non-binary identities, feel supported to make informed decisions about the treatments that are right for them. The service environment will need to be inclusive and accepting enough that all trans people feel able to speak openly about their health and other aspects of their lives, which many trans people currently feel unable to do. To allow this, the protocols followed by services will need to be similarly inclusive. As discussed above, further consultation with trans people will be essential in making these changes to services.

Waiting times are the main source of distress for trans people in Scotland, and can have serious consequences for mental health. Reducing waiting times should be a priority for services, and should allow trans people to be more open about their views without fear of intolerable further delays in accessing gender-affirming treatment.

## Chapter 5: Comparative Needs Assessment

### Services Elsewhere in the UK: Four Nation View

The first section of this chapter considers treatment pathways for gender identity services in England, Wales, and Northern Ireland, aiming to build a four nation view of how services work together and separately across the UK. Descriptions were sought from online sources and by reaching out directly to providers where clarification was necessary. Where possible, comparisons are made between Scottish trends in number of referrals/waiting times collected as part of this HCNA and those of gender services in the rest of the UK.

#### England

In England, the adult pathway is comparable with that in Scotland and also based on the WPATH. However, there is no stipulation within the Interim NHS England Gender Dysphoria Protocol and Guideline 2013/14(96) that patients can self-refer to a GIC as recommended in the Scottish GRP. For some treatments in England (including hormone therapy and mastectomy/chest reconstruction) the support of two clinicians is required who are directly involved in the patient's care.

As in Scotland, a 12 month period of real life experience is required before any genital surgery can take place. Treatments and surgeries not listed within the Gender Dysphoria Protocol can only be provided on an exceptional clinical need basis following consideration by the patient's Clinical Commissioning Group (CCG), including breast augmentation and facial feminisation surgery.

English surgical providers and GICs are required to publish their monthly waiting times data, measuring compliance with an 18 week waiting standard(97), although waiting times for all providers are in excess of this. This differs from Scotland where GICs are exempt from reporting waiting times.

For those under the age of 18 the pathway involves an initial appointment with their GP, with possible referral to Gender Identity Development Service (GIDS) at The Tavistock and Portman NHS Foundation Trust, London – this is the service that most young people under the age of 12 years would be referred to from Scotland before transition of care to the Sandyford YP service. A satellite clinic also operates in Leeds. Patients are offered an initial assessment, usually over three to six appointments with one or two mental health professionals, and should be seen with 18 weeks of referral.

From August to October 2017 there was a UK-wide public consultation on proposed changes to NHS England's Gender Reassignment Surgical Service Specification. As NHS England provides all gender reassignment surgeries for Scottish trans individuals, such changes may impact the Scottish pathway. The draft proposal included changes to the circumstances in which additional surgery or corrections would be carried out by NHS England specialist services, with this no longer being

covered by their commissioning remit if the request were made over 18 months after initial surgery(98). The results of the consultation have yet to be announced.

## **Wales**

Gender identity services in Wales are currently under review and in the process of major revision and development. The existing Welsh care pathway begins with referral from the patient's GP to a local NHS consultant psychiatrist who determines if the patient has a diagnosis of gender dysphoria. If so, the clinician will refer the patient to the designated gatekeeper within their local Health Board. The clinical gatekeeper will then approve the referral and forward it to the Welsh Health Specialised Services Committee (WHSSC)(99) for authorisation. As Wales does not currently have a GIC, WHSSC then notifies the London GIC (Tavistock and Portman NHS Trust) that the referral has been approved, and will notify the referring consultant that they can proceed with referral to the GIC assessment service. If diagnosis of gender dysphoria is confirmed at their assessment, the patient follows the London GIC care pathway. Any surgical intervention would take place at Charing Cross Hospital and University College London Hospitals.

In line with England, requests for any of the procedures which are not part of WHSSC planned services, and so not routinely approved, will only be considered by the All Wales Independent Patient Funding Panel if exceptional circumstances are demonstrated. These include breast augmentation, voice modification surgery, and baldness related treatments.

In response to an increase in demand for transgender health services in Wales, long waiting times for initial appointments, and higher costs, anxiety and stress associated with travel to London, a new model of care is to be introduced. This will involve the establishment of specialist hospital based services in Wales and improvements to community-based care, with a network of GPs across Wales with a specialist interest in gender identity, supported by a Welsh Gender Team. The latter is expected to accept new referrals and repatriate appropriate individuals using services in London currently on waiting lists for treatment. This is to be done in partnership with the GIC in London, where pathways will remain open for individuals with complex needs or those requesting gender reassignment surgery(100)(101).

There is no specific pathway for under 18s in Wales and this group are referred to GIDS within The Tavistock and Portman NHS Foundation Trust, though may be seen at a satellite Tavistock clinic which takes place in Cardiff approx. quarterly.

## **Northern Ireland**

There are no formal published gender identity treatment pathways for adult, child or adolescent patients in Northern Ireland, although guidance has been issued by the Royal College of General Practitioners in Northern Ireland on how transgender patients may be adequately cared for(102).

The Brackenburn Clinic in Belfast provides a Regional Gender Identity Service within mental health services, offering assessment, psychological support and onward referral for further treatment. The service works with those over the age of 18 who have a clinically significant psychosexual/gender identity disorder suitable for intervention, with capacity to engage with an appropriate psychological therapy, and who are relatively stable from a psychological, physical and social perspective. After an initial assessment period, patients are offered referral to a similar variety of services as in the rest of the UK, including hormone therapies locally and surgical services in England (103)(104)(105). The service accepts referrals from GPs and other health professionals, and the current waiting time for an initial appointment with the service is at least 12 months.

For those under the age of 18 a service entitled 'Knowing Our Identity' in Belfast supports trans and gender variant children and adolescents. The service accepts referrals from health, social services, education, and CAMHS, and can speak with parents, guardians and young people directly about referrals. The standard referral pathway is referral from a GP to CAMHS and then onto the service, though children and adolescents are also able to self-refer. The service provides counselling, family and peer support, and mental health support services. Patients can also access hormonal treatments from age 15 and up, subject to assessment. Upon reaching 18 the patient can then be transferred to the adult service(103).

## **Comparison of Referral and Waiting Times for GIC Appointment**

### **Number of Referrals**

Online searches provided a range of data on referral numbers to GICs in England, though not for the Brackenburn Clinic in Northern Ireland; Wales does not currently have a GIC for which to compare figures. The findings are summarised below.

There have been historical increases in the number of referrals to six of the seven adult clinics in England for whom data were reported (10):

- Charing Cross – 498 referrals in 2006/7 to 1,892 in 2015/16
- Nottingham – 30 referrals in 2008 to 850 in 2015
- Exeter – 31 referrals in 2005/6 to 636 in 2015/16
- Sheffield – 8 referrals in 1998 to 301 in 2015
- Northamptonshire – 88 referrals in 2014/15 to 466 in 2015/16
- Leeds – 131 referrals in 2009/10 to 414 in 2015/16

Due to the lack of national data or data from several consecutive years, it was not possible to determine the degree to which these increases in adult referrals were similar to those experienced in Scotland.

The young people's Gender Identity Development Service (GIDS) within The Tavistock and Portman NHS Foundation Trust has also seen an increased number of referrals, although it reported a smaller rate of increase in 2016/17. There has been a

proportional increase in presentation of those assigned female at birth (Table 14)(106)(107).

**Table 14: Number of referrals to GIDS with percentage change (derived from (107))**

Year	Number of referrals	Percentage increase (%)
2009/10	97	-
2010/11	139	43
2011/12	208	50
2012/13	314	51
2013/14	468	49
2014/15	697	49
2015/16	1,419	104
2016/17	2,016	42

These percentage increases in referrals are very similar to those experienced by the Sandyford YP service, who saw a 103.2% increase from 2014 to 2015, and a 43.0% increase from 2015 to 2016.

### Waiting Times

It is likely that waiting time estimates for other centres will be based on different methodologies than that used in this report, with many using best guess rather than calculated average. This should be considered as a potential limitation if making direct point comparisons between centres, though is less of a limitation where making general comments on comparison of trends over time.

In 2015, the average waiting time for a first appointment for adult GICs in England was 47 weeks (approx. 329 days)(108). This is in keeping with the Scottish picture, where at the same period service data from Scottish GICs showed very similar mean waiting times of 323 days.

By November 2017 waiting times for GIC appointment at the seven English GICs were reported to have increased to between 12 and 30 months (mean 18 months/approx. 540 days)(109). This is in contrast with Scottish GICs, where service data shows that mean waiting times for Scottish GICs fell over the same period, to 260 days in 2016 and provisionally 114 days in 2017. Waiting times for the Brackenburn clinic in Northern Ireland at the same period were reported to be 2 weeks (14 days) to 14 months (approx. 420 days), with no mean date supplied for direct comparison, (109) however these figures are similar to the provisional range of waiting times for Scottish GICs in 2017 (0-407 days).

The current waiting time for the young people's GIDS in London is at least 12 months (110). This is slightly higher than the current provisional 2017 mean waiting time for the Sandyford YP clinic in Scotland (294 days).

## Summary

Services offered to trans people across the UK vary according to their constituent country. The Scottish model of several GICs approximates most closely to the English model, though there are some key differences, in particular the provision of gender reassignment surgery within the same country and the required reporting of waiting times. A further significant difference is the presence of a nurse-led service at Lothian GIC in Scotland, which may have had an impact on reducing waiting times. The marked increase in referral numbers to GICs in Scotland over the last several years is reported elsewhere in the UK. Waiting times for Scottish adult GICs are lower than in England, and have nationally decreased since 2015 in contrast with trends in England. Waiting times for GICs for young people are similar in Scotland and England.

## Services Elsewhere in the World: International Perspective

The second section of this chapter considers the evidence on provision of gender identity/trans services and service user experience in nine countries outwith the UK for comparative purposes, to identify whether there are common models of good practice or developing trends in trans healthcare. The countries selected (Australia, New Zealand, the United States, Canada, Norway, Sweden, Denmark, France, and Belgium) were largely chosen due to the limited availability of data rather than deliberate design. The information identified often focuses on trans experiences of healthcare access in general, without separating out those who identify as having binary or non-binary gender identities. A further limitation is that research often only incorporates trans people under the wider LGBT umbrella, meaning it can be difficult to tease out trans experiences within this context. While an original aim of this comparative section was to compare changes in referral patterns and waiting times in Scotland with similar international centres, this was only possible in a limited number of cases due to lack of available data.

### Australia

Evidence suggests there are significant barriers for trans people seeking access to healthcare in Australia, largely resulting from a lack of public funding for hormones or surgery, issues identifying doctors willing to prescribe and monitor hormone therapy or adopt a more flexible approach to transition (such as the informed consent model), and treatment pathways that may not reflect the differing needs of non-binary individuals(111)(112). A recent Australian study found that non-binary individuals seek treatments such as hormones to a lesser extent than trans people with a binary gender identity, either because they do not fulfil the needs of the individual for physical change or they feel medical professionals will not adequately understand that their identities fall outside those of a typical trans experience(113).

There is one adult GIC equivalent in the whole of Australasia, the Monash Health's Gender Dysphoria Clinic (GDC) in Melbourne, which receives referrals from across Australia, and one young person's GIC at the Melbourne Royal Children's Hospital (RCH). Both report significant increases in referrals in recent times (for the RCH, from 3 referrals during 2003-2007 to over 100 in 2014)(111). Patients may be referred from

specialist GPs (those providing sensitive, LGBT inclusive practice) and non-specialist GPs; the former can refer adult patients to non-clinical services (e.g. hair removal, SALT). All GPs can refer adults to the GDC for psychological assessment or to a private clinical psychologist, and access to hormone therapy is determined at this point. GPs can prescribe, monitor and manage hormones if the GDC confirms suitability. If the patient requires surgery then this may be provided by the GDC, other private sector providers in Australia, or overseas(112). Waiting times can be long for GDC services, but less so for those seeking appointments privately, introducing inequity. Both clinics generally follow WPATH guidance. The average age of presentation to RCH as reported in 2015 was 12.3 years, and the average age of presentation to the adult GDC was 40 years(114). These differ fairly markedly from the equivalent values in Scotland, where these were 14.1 years and 27.4 years respectively.

The legal situation in Australia differs from that in the UK. Families of trans young people can access hormone blockers to suppress puberty, though these are not funded (costing approximately \$5,000 per patient per year), but they must apply for court approval to begin hormone treatment to transition if they wish to do so between 16 and 18 years of age. Significant financial costs, as well as emotional stress, are attached to this process(115). Access to some Medicare (universal health coverage) and government funded medications is currently dependent on identifying as male or female, though this is changing. Medicare provides a rebate for only parts of surgeries and does not subsidise surgical procedures identified as cosmetic, including some gender affirmation surgeries, making treatment unaffordable in practice for many. No FtM genital surgery is conducted in Australia. In addition to this, the surgical procedures required to meet the criteria for a change of legal sex vary across states and territories, and the requirement to be unmarried in order to change sex legally means that transgender individuals must choose between legal recognition of their affirmed gender and the legal recognition of their primary partnership(112).

Healthcare provision for trans people in Australia is perceived by some service users as poorly co-ordinated and characterised by ill-defined care pathways, long waiting lists, lack of advice and support, inequity in access to services, lack of referral by health professionals such as GPs to appropriate specialist services, and high costs of care (112). A recent survey of patient satisfaction at the GDC is generally positive, although waiting times for a first appointment are highlighted by patients as a significant obstacle to accessing timely care(116).

### **New Zealand**

As in other countries the prevalence of trans identity in New Zealand is not clear, however proposed changes to the gathering of national statistics about transgender and gender diverse individuals are anticipated to positively impact on health data and research about these groups. This will take the form of the inclusion of a gender identity question in the 2018 Census of Population and Dwellings by Statistics New Zealand(117).

For those seeking to transition in New Zealand, where WPATH Guidelines are applied to the local context in the absence of a central GIC, a diagnosis of gender identity disorder is required before surgeries may be accessed. Individuals must also receive more than 12 months of continuous hormonal treatment, live for at least two years in their chosen gender, and provide reports from two psychiatrists and a psychologist. Public funding for gender reassignment surgery appears to be heavily restricted, with less than 5 individuals every two years able to access a special 'high cost treatment pool' provided by the Ministry of Health for treatments not funded by the public health system. District Health Boards (DHBs) apply to the Ministry of Health for funds on a patient's behalf. Four types of hormone treatments however are fully funded(118).

A survey of physicians providing a secondary level service to trans people suggests that there are significant barriers to transgender care in many regions of New Zealand. Small numbers of specialists manage hormone therapies, although there is at least one specialist in most DHBs. Those able to pay can access counselling or psychological assessment, access to which may be restricted in the public sector, impacting on the ability of clinicians to prescribe hormones if a psychological assessment hasn't taken place. Most DHBs do not support surgeries in the public sector, possibly reflecting local surgical guidelines placing little weight on gender reassignment. Therefore, both psychological and surgical services are less accessible via the public system compared with the private system, meaning that lower socioeconomic groups are placed at a disadvantage(119).

### **United States**

Trans people in the US experience various barriers to healthcare including the limited availability of providers with adequate training to treat trans patients in a culturally competent manner, costs associated with treatment, discrimination and fear of discrimination, and lack of trans healthcare services and differential access to care by US state(120)(121)(122)(123)(124). Prior to the introduction of the Affordable Care Act (2010), which banned discrimination on the basis of sex, many carriers refused to insure trans people, arguing that being transgender constituted a pre-existing condition. There has since been a rapid rise in insurance coverage for healthcare services related to gender transition(125). Federal law prohibits discrimination in healthcare on the basis of gender identity, but access to healthcare for transgender groups in the US varies from state to state(126). State coverage for transitioning is explicitly covered by Medicaid policy in 13 states and Washington D.C., but a further 37 states have either no explicit policy in relation to transitioning or trans healthcare in general, or explicitly exclude trans people from Medicaid coverage(127). In terms of private insurance, in 37 states there are no laws that provide trans people with private insurance protections(126).

It is assumed that providers of healthcare services to trans people will use WPATH guidelines, as well as the Guidelines for the Primary and Gender-Affirming Care of Transgender and Gender Non-binary People set out by the Center of Excellence for Transgender Health (University of California), which aims to complement WPATH and

increase access to comprehensive, effective, affirming health services for trans groups. The Guidelines emphasise that, in contrast to past practices where a set pathway required a psychological assessment followed by hormones and genital surgery, the current standard of care is to allow each transgender person to seek only those interventions they require. While historically a referral letter from a mental health professional was required prior to initiation of hormone therapy, many providers have been using an informed consent pathway to hormone initiation, in line with WPATH recognition of both routes(128).

The impact of the experience of healthcare and transitioning on trans people in the US is captured in the 2015 national US Transgender Survey. Most respondents (86%) reported that they were covered by a health insurance or health coverage plan. However, when asked about their experiences in the past year, 25% of respondents had experienced a problem with their insurance in relation to being trans, such as being denied coverage related to transition or hormones. The survey highlighted significant differences in treatments desired by those with binary and those with non-binary gender identities: for example, a large majority of trans men and trans women (95%) wanted hormone therapy, compared to 49% of non-binary respondents. Trans men and trans women were about five times more likely to have ever had hormone therapy (71%) than non-binary respondents(13%). In relation to denial of service, 13% of respondents reported that they were denied coverage for services often considered to be gender-specific e.g. cervical smears. Denials for hormone coverage differed by gender, with trans men (32%) and non-binary people AFAB (36%) more likely to report being denied hormone coverage than trans women (18%) and non-binary people AMAB (16%). 55% of those seeking transition-related surgery were denied coverage. Trans men (57%) were more likely to be denied surgery coverage than trans women (54%), non-binary people AFAB (49%) and non-binary people AMAB (35%)(129).

## **Canada**

In Canada, in line with other high-income countries, the known trans population is following a similar upward trajectory (130)(131). The thirteen Canadian provinces and territories are individually responsible for providing federally mandated essential medical services through a universal, publicly funded, health insurance program(132). Trans Care BC in Vancouver, British Columbia would appear to be the only example of a province-wide system aimed at promoting best practice among primary care providers and equitable access to services for trans people. Health navigators, nurses, peers and support staff, with access to a doctor, co-ordinate support and identify treatment providers within British Columbia or refer patients to other locations for certain surgeries. A toolkit(133) has been developed, intended to support GPs and Nurse Practitioners in their service provision to trans people(134).

In general however, trans people appear to be medically underserved, with healthcare providers often perceived as lacking knowledge about transgender health issues and providing low numbers of approvals for surgeries and hormones(135)(136)(137). GIC equivalents are limited to major cities and coverage for gender affirming surgical care

varies from province to province with regard to which surgeries are covered and the amount of coverage provided(138). There is no coverage for some procedures (e.g. facial feminisation) in any state, and only some provinces provide funding for procedures to be carried out abroad(139). While coverage is expanding in terms of the number of jurisdictions that provide coverage and procedures covered, a two tiered system means that those not able to pay for treatments experience delays and barriers to accessing treatment(140). In some provinces, such as Ontario, primary care physicians and nurse practitioners are able to assess and refer individuals for transition-related funding, however in others this is reserved to mental health services (138).

There is little evidence about the experience of non-binary people in Canada, however, a recent small national survey of trans people aged 14-25 years indicates that healthcare related issues may be more acute for non-binary youth than binary trans youth. Non-binary youth were less likely to have a family doctor, and where they did have a doctor, they were less likely to know about the individual's trans identity or experience. Non-binary respondents were also less likely to require hormone therapy, but more likely to experience barriers to care when hormone therapy was wanted (131).

## Europe

The European Court of Human Rights established in 2010 that European Union (EU) states must provide for the possibility of full gender reassignment, offering hormone treatment, gender reassignment surgery or other medical interventions(141). Individual member states within the EU are responsible for the provision of healthcare to trans people in their own population, leading to various forms of service delivery which reflect the differing ways in which healthcare is financed in these countries as well as attitudes to trans people. Experiences of trans healthcare will therefore differ by member state, with a mix of full publicly funded healthcare support for transitioning, both state and private provision, or the absence of provision altogether reflecting discrimination and stigma, weak legal recognition of trans people, and prevailing religious views.

The available evidence, some of which is now dated, indicates that access to and funding for healthcare, hormone treatments, and surgery for trans people across a number of EU member states has not been fully achieved in spite of the position of the European Court(50)(142). In addition to this, for legal gender recognition around 20 countries in Europe require the sterilisation of trans individuals, and 36 require a mental health diagnosis including the UK, Spain, Germany, Italy, Sweden, Finland, Switzerland, and Belgium(143).

The Council of Europe's Commissioner for Human Rights has recommended that member states should abolish sterilisation and compulsory medical treatments as a prerequisite for a change of name and gender, and has also advocated amendments to international classifications of diseases classifying trans people as mentally ill(144).

There has been a shift therefore in a limited number of member states towards abandoning requirements for compulsory medical treatments or for the diagnosis of mental ill health, including the Spanish region of Catalonia(145) and Denmark(146). The Scottish Government is currently consulting on a proposal to make changes to the 2004 Gender Recognition Act along these lines, seeking to adopt a self-declaration system for legal gender recognition and removing the requirement for medical evidence(147). This consultation also seeks views on extending access to legal gender recognition for those under 16 years and non-binary individuals.

More detailed descriptions of gender identity pathways and services were sought for a small sample of EU member states, and are provided below.

### **Denmark**

As mentioned above, Denmark has sought to redefine being transgender, rejecting its classification as a mental illness(148). This means that the previous requirement that Danish trans people accept a diagnosis of transsexualism using the ICD code in order to receive hormone treatments, surgeries and eventually genital reassignment surgery has been revoked. National medical guidelines will instead be used that do not refer to mental illness or sexuality. However, access to treatment will continue to require an initial assessment of the patient. The Danish health service has now also extended treatment to provide hormone blockers to delay puberty for children from the age of 12 (146).

### **Norway**

Recent legislation, based on the principle of self-determination, means that Norwegians will also be able to change gender without the need for sterilisation or medical diagnosis (149). Norway is currently reviewing the provision of care to trans people at national and local level with the view to developing a more accessible and efficient service. The number of individuals seeking treatment has increased and the number of those patients given a diagnosis of transsexualism has increased significantly in recent years, from 35 patients being registered in 2010 to 449 in 2016. At the end of 2016, 331 patients were admitted to the National Treatment Service for Transsexualism in Oslo. 45% of patients were children and adolescents under 18 years of age, 55% were adults over 18 years. This ratio is fairly different from the Scottish data collected from 2016 as part of this HCNA, where 74.2% of referrals were to adult GICs (n=525) and 25.8% were to the Sandyford YP service (n=183).

Where patients contact GPs they may be referred to a District Psychiatric Centre (for adults) or to the Psychiatric Service for Children and Adolescents, or to an approved private psychologist or psychiatrist covered by a contract with the regional health authority. They consider patient needs, and an assessment will be made on what type of specialist care is appropriate, including a possible referral to the National Treatment Service for Transsexualism where high-level assessment and treatment of trans patients takes place, including hormone treatment and gender reassignment surgery. There are variations in how long the assessment takes. Patients who have been

assessed and then rejected by the national service will be referred back to the ordinary specialist health service. No special services for this group are currently available within the regional hospital sector.

The average waiting time in mental healthcare for children and adolescents from referral to provision of healthcare in 2017 was around 54 days. Average waiting time in mental healthcare for adults has been around 49 days. Both of these figures are considerably shorter than the respective waiting times in Scotland (294 days and 114 days respectively). There is a long wait for surgical procedures in Norway; 75% of patients referred for surgery in 2013 (n=12) were still awaiting completion of this in January 2015(150).

### **Sweden**

For those seeking gender reassignment in Sweden, a letter of referral is provided to a gender identity investigation team (GIC equivalent) comprised of physicians, welfare officers and psychologists. The investigation includes interviews, and diagnosis may take around one year, with initiation of 'real life experience' in the preferred gender while maintaining contact with the investigation team. A gender dysphoria diagnosis allows for hormone treatment and chest surgery to be offered. For a legal gender change and genital surgery, a transsexualism diagnosis is required. Regional County Councils have overall responsibility for healthcare in Sweden, which means that waiting times vary across the country(151).

Non-mandatory guidelines frame how GICs provide care for adults and those aged under 18; however, the approach varies across six clinics providing treatments. Treatment is characterised by long waiting times for assessment, for which a referral is required from a psychiatrist within general healthcare (which may be difficult to obtain, further lengthening waiting times). However, some GICs now accept direct referrals from patients themselves (152). All costs for medical care and pharmacological treatments are available via national health insurance, presenting less of a barrier to treatment for lower socio-economic groups than described in other countries (153).

In spite of this, respondents participating in several small surveys report high levels of disability and poor health, suicidal thoughts, and reluctance to seek help due to fear of prejudice from healthcare providers. The central criticisms revolve around perceptions of healthcare staff as lacking knowledge, their use of inappropriate questioning and unnecessary focus on gender identity(153)(154). Additionally, there are frustrations around waiting times for referral to GICs and perceptions among respondents of a need for training for health professionals about transgender health, as well as access to information about trans-friendly doctors or clinics. Recent survey work indicates that non-binary people in Sweden have worse self-reported health and more self-reported disability than other trans people. Responses suggest that negative healthcare experiences are attributable to mis-gendering or healthcare staff not

understanding non-binary identities. Only 3.5% of non-binary respondents stated that they can always live according to their gender identity(152)(155).

### **France**

Access to hormone treatments and surgeries in France depends on a psychiatric diagnosis. Medical teams, based in the major cities, provide a psychiatric assessment undertaken by two psychiatrists and a psychologist which usually takes six months. A medical commission then determines which health treatments, hormones and surgeries, each person should access. Transitioning in France requires the production of a psychiatric certificate testifying that the individual has been diagnosed with gender identity disorder. Clinicians continue to use ICD codes to diagnose transsexualism in their work, reflecting their use by the wider French health system, although the Ministry of Health has previously determined that transsexualism would no longer be classified in the category of 'mental disorder' for eligibility for reimbursement of medical costs via medical insurance. The acquisition of a certificate requires 2 years of psychiatric follow-up and a 'real life' test. It is only then that an individual may undergo hormonal and surgical treatments, accessing coverage provided by health insurance schemes. Following completion of the transition pathway, i.e. receiving genital surgery, an individual may then request a change in civil status through the courts, although some courts have been approving applications for a change in civil status for individuals who have not undergone genital surgery (156)(157).

### **Belgium**

The Belgian government has moved towards removing the need for sterilisation and a mental health diagnosis in order for legal gender recognition to take place(158). Transgender health treatments in Belgium are provided via hospitals in Ghent and Liège. It takes around six months to establish a psychiatric diagnosis at the Ghent University Hospital; the diagnostic period involves usually six sessions with mental health professionals on a monthly basis, and may take up to one year. Hormone treatment is accessible after a diagnosis, and is available to minors. Genital reassignment surgeries are available for trans women one year after hormone treatment, and two years after for trans men. For the latter, waiting periods are longer due to the limited availability of surgeons. Genital reassignment surgery is practiced in a way that involves the removal of reproductive organs(157). The costs of care (consultations, hormones, surgery, epilation) and the lack of clarity surrounding the reimbursement of such costs by insurers and the National Institute of Health and Disability Insurance can impose financial barriers(159).

### **Summary**

Services offered to trans people in high-income countries around the world vary markedly according to the system of healthcare provision, legal protections, and societal attitudes. Long waiting times and lack of understanding and support from healthcare staff are consistent sources of anxiety for trans people across countries, with non-binary individuals in particular noting difficulties achieving acceptance.

Inequalities in access are most commonly mentioned in healthcare systems which involve out-of-pocket costs or barriers to trans people achieving health insurance, though availability of service is also an issue. In several European countries there has been a move towards self-declaration of gender identity and removal of the need for a mental health diagnosis to access services and legally change gender, in keeping with planned Scottish Government legal changes.

### What Does This Mean For Us?

The issues reported by trans people in Scotland in relation to accessing gender identity services is similar to the experience in many other countries. Our gender identity services have much in common with those in the rest of the UK, though on some measures such as waiting times we appear to be performing slightly better. Worldwide, there is more inequality in accessing services reported where there are legal or financial costs associated with treatment, and we should ensure there remains strong protection against this.

In contrast with many countries who provide trans healthcare services, there are no surgical services for gender reassignment provided in Scotland. This is something which could be considered as a future option to reduce the travel and financial burden on Scottish trans people who want to undergo surgery, but would require careful planning and likely take many years to implement fully.

## Chapter 6: Statement of Need

This HCNA set out to inform planning of national gender identity services. A literature review, data analysis, and interviews with stakeholders were used to gather this evidence. This section draws together the findings and considers them against the principal aims of this HCNA:

- To identify the level of need and map current service provision
- To understand the service user experience and access to services
- To understand how the current gender reassignment protocol is being adhered to and what support services are important to users
- To identify the inequalities resulting from current service provision

Finally, the findings in relation to these aims are considered according to what models of care might be most appropriate to consider for those planning service provision going forward.

### Identifying the Level of Need

#### Prevalence of Trans Identities in Scotland

It was quickly evident from the literature that no single figure for the prevalence of people with trans identities exists, providing a challenge for health service planning. There are a number of reasons for this, including a lack of routine data (e.g. the census does not include questions on gender identity, and it may not be appropriate for it to do so for reasons of privacy(160), differences in defining trans identities, and difficulties in asking appropriate questions. The evidence suggests a range of prevalence estimates, derived in a variety of settings and using a range of methods. These can be used to provide crude estimates of the number of trans people in Scotland. Given an estimated 2016 Scottish population of 5,404,700 people (918,799 under 16 years old, 4,485,901 aged 16 years and over) the following estimates could be derived (Table 15)(161).

**Table 15: Estimates of the size of the trans population in Scotland derived from literature**

Source	Prevalence estimate	Estimated size of trans population in Scotland
Reed <i>et al</i> * (32)	20 per 100,000	Approx 900 adults
Collin <i>et al</i> (33)	9.2 per 100,000	Approx 400 adults
US estimates (Crissman <i>et al</i> and Flores <i>et al</i> (28, 35)	0.53% of adults (95% CI 0.46, 0.61)	Approx 23,775 adults (95% CI 20,635-27,364 adults)
Clark <i>et al</i> (29)	1.2% of young people	Approx 11,000 young people

\* This paper also provided higher estimates of prevalence.

Given that over 1,800 adults have been referred to Scottish GICs between 2014 and 2017 (41 per 100,000 adults in 4 years) the former two estimates appear extremely low, and can probably be disregarded. True prevalence may be more in line with the findings from the US, which was calculated from self-reported gender identity and is the most often quoted likely prevalence i.e. 0.5% of the population, but this is considerably higher than the numbers referred to services. Almost 600 young people have been referred to the Sandyford GIC between 2014 and 2017 (65 per 100,000 young people in 4 years); compared to Clark *et al's* New Zealand estimate again this is markedly lower. Neither of these estimates take into account any potential differences between population structure or cultural context in Scotland and the countries in which they were measured.

As GIC services in Scotland have not yet been established for long, and demand is known to be increasing, it is very difficult to gain a true idea of prevalence from these Scottish referral figures. It is highly likely that a proportion of trans people in Scotland either have not yet presented to NHS services or do not want or need to present, making any judgement of prevalence from usage of these services an underestimate. To firmly establish the prevalence of trans identities in Scotland, a nationally representative population survey is likely to be required. However, what they are likely to be more useful for is planning future NHS service provision, particularly when considered in the context of trends in referral numbers as discussed below. It is worth noting that many individuals who do not present to NHS services may still seek support from the third sector and peer support groups in relation to broader trans-related health and wellbeing needs, which will not be captured in these data.

### **Increasing Demand for Gender Identity Services**

There is national and international evidence that demand for gender identity services has been markedly increasing. The increase in referral numbers to Scottish GICs is also being experienced by other GICs in the UK. Furthermore, community services have also seen an increase in demand – where there are barriers to trans people seeking healthcare, third sector and community support is likely to be particularly key in helping individuals overcome these barriers. This increase in demand has put all gender identity services under pressure despite some increases in capacity. The result has been long waiting times and concern from specialists and other stakeholders about the impact of this on patients, and dissatisfaction from service users. The increase in demand appears to have happened in recent years, though there is evidence from Scottish GIC data that the rate of increase may have begun to slow. This has also been reported elsewhere, with one GIC for young people in England recently reported a slowing in the rate of increase(106). However, even if this represents a sustained slowing of the increase in demand it does not necessarily follow that it represents a meeting of true need and expressed need, as it may also be being influenced by supply i.e. individuals may be aware of long waiting times and therefore be increasingly reluctant to present to services.

It is unclear whether the increase in demand represents an increase in prevalence of people with trans identities, or a greater demand for health services from an existing group of trans people. While the evidence gathered for this HCNA cannot definitively answer this question, based on the evidence from specialists the second option appears most likely, meaning that projections of how this greater demand may express itself in future are of paramount importance for good service planning.

Opinion in the literature and from specialists highlighted a range of potential explanations for the increase in demand. These include (positively) changing public and individual perceptions of trans identities, increased awareness of trans identities, increased media coverage of trans people and the availability of social media enabling people to more easily access information and support on trans identities, greater availability of specialist services, and increased legal protections. Recent developments, including government proposals to make gender change easier and suggestions to move trans identities out of the mental health section in the ICD-11 (57), suggest that the positive changes already seen are likely to continue to develop. This has the potential to further increase demand for gender identity services if trans people feel increasingly able to come forwards and present for gender affirming treatments.

Further to the increase in demand, the characteristics of the population presenting to GICs appears to be changing. Evidence from the literature, data, and from stakeholders suggests that the people presenting are younger (with younger adults and more children being referred), and there are more non-binary people and trans men presenting. There was also reported to be an increase in those presenting who are questioning their gender identity, rather than it being firmly set. These individuals are likely to have different healthcare needs, and services will need to adapt to accommodate these changes. Linked to these changes in demand and their potential explanations is the possibility that young people's views of gender are changing, moving away from traditional views of male and female to a more fluid and less defined view of gender. There are reports that this may be happening (66)(67), and this potential change was highlighted in the interviews. However, a limited amount of research evidence was found in this area, perhaps because it is a very new change.

### **Mapping Service Provision to Need**

Considering how the identified need is distributed geographically, it seems from the data collected that services are appropriately picking up trans individuals in each of the fourteen health boards as would be expected, with slightly more representation from urban centres for adults. However, that does not necessarily mean that individuals in each health board have equal access to services, which will be explored further when considering inequalities in access below. It was noted that the adult population of NHS Lothian appears to be over-represented in referral numbers, which could be due to either greater underlying need within this population, a higher proportion of this need being expressed than in other areas, or services factors such as accessibility. To what degree each of these may be responsible is not discernible

from this HCNA, however further work to consider this would be useful. Of interest, third sector and peer support for trans adults is more established in Edinburgh, and includes supporting individuals to overcome the barriers they are experiencing in relation to expressing their gender identity and seeking healthcare.

While waiting times for adult GICs have on average been falling nationally, this is largely being driven by a sustained decrease at Lothian GIC, and waiting times at all other centres have either stayed approximately the same or increased during the period. This indicates that there is currently a long period where the needs of individuals are not being met by existing healthcare services with the exception of the few areas where pre-GIC services exist, and interviews with stakeholders and service users illustrate that this can have serious consequences for the health of trans people.

A further gap identified by some stakeholders between need and current service provision is the focus of services on assessment of readiness for intervention, rather than discussion and exploration of individuals' feelings on their gender identity. This in combination with long waiting times was felt to increase the likelihood of service users withholding information for fear of being held back from treatment. Given the reported increase in presentation of those in the early stages of questioning or exploring their gender identity, there may be a need to adapt service provision to better accommodate these people rather than continuing with a purely assessment-based model e.g. through provision of group sessions, counselling etc., to avoid individuals progressing along a medicalised pathway that may not suit their goals. There is a clear potential role for third sector organisations in this, who are able to work with those in the early stages of questioning or exploring their gender identity in a way that is less focused on a medicalised pathway, and more on creating an environment where individuals can openly explore their goals and feelings. There was also a sense that the needs of non-binary people may be less well met than other trans people, though interviews with service providers and other stakeholders indicated that this may be improving.

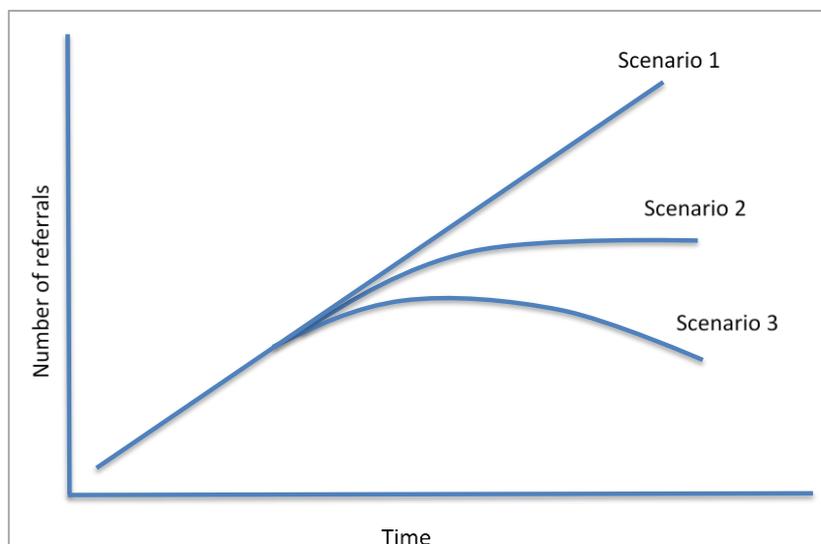
### **Future Projections of Demand**

No future projections of demand for gender identity services were found in the literature. Therefore, the following projections were based on the evidence presented throughout this HCNA from service usage data and stakeholder interviews, using what evidence there is to provide a basis for assessing and planning for future demand. The increases in demand for gender identity services are recent, are likely due to complex social and cultural reasons rather than having a single, straightforward explanation, and are continuing to evolve. This presents a challenge for healthcare planning that it is difficult to provide an accurate and reliable response to, therefore services are likely to require to be adaptable. More evidence may emerge on the changes in demand, and ongoing robust data collection by GICs will be essential in monitoring the outcome of any predictions based on existing data to correct these if they are inaccurate.

Three potential future scenarios have been considered (Figure 2): the possibility of a genuine increase in prevalence of trans identities, which would present as continuing

increase in demand (Scenario 1); a responsive increase in expressed need as a result of increasingly accessible services, which would present as an increase followed by a plateau (Scenario 2); and a waning of overexpressed need resulting from over-supply, which would present as decreasing demand (Scenario 3).

**Figure 2: Potential scenarios in change in number of referrals over time**



<b>SCENARIO</b>	<b>DESCRIPTION</b>	<b>COMMENTS</b>
<b>1</b>	<i>Continued increase in demand</i>	<i>Specialists commented that demand cannot continue to increase indefinitely. If this scenario were to occur at the most recent rate of confirmed increase in referral numbers from 2015 to 2016 (43% for young people and 25% for adults) GICs across Scotland could have as new patients: 2017 – 262 young people and 656 adults 2018 – 374 young people and 820 adults 2019 – 535 young people and 1025 adults</i>
<b>2</b>	<i>Increase followed by a plateau</i>	<i>Many specialists commented that this is a possible scenario, although they were unclear when the plateau would occur. There may be some early signs of this happening if the Sandyford referral acceptance rate stays the same as previous years in 2017, as using these predictions for rate of increase (0% for young people and 3.8% for adults) the same number of new patients would be: 2017 – 183 young people and 545 adults 2018 – 183 young people and 566 adults 2019 – 183 young people and 587 adults</i>
<b>3</b>	<i>Decrease in demand</i>	<i>No specialists commented that they thought this would happen and there was no evidence in the literature or from the data of this view either. It is perhaps possible that this could happen in the long-term if the medical approach to trans healthcare changes or if trans identities become normalised in society so fewer people seek healthcare input.</i>

Expert opinion, obtained through the interviews, suggests that Scenario 2 is most likely, and the data presented in this HCNA including provisional referral data from 2017 support that this may already be happening. If this were to continue, it is important to consider how services will need to change to cope with this sustained increase in demand compared with several years ago. These include adult GICs accommodating an increased number of people being referred from young people's GICs, increased demand for gender affirming interventions such as hair removal and hormone prescribing, and increased demand for community support services.

A particular issue may be with regards to access to gender reassignment surgery. As discussed, there is currently no provision for this surgery in Scotland, with individuals being referred to surgeons in England. However, there are concerns about waiting times for surgery and the limitations of capacity nationally. Given the potential future increase in demand for surgery amongst Scottish patients, particularly for patients where there is a prolonged delay between presentation and referral for surgery (such as young people), the development of surgical capacity nationally in Scotland may be important. This would require consideration of workforce planning and training opportunities for potential surgeons. It is noted that data on surgical referrals presented here indicate that in actuality these have decreased in the first three quarters of 2017, however a full year's worth of data would be required to confirm this, and also this may too be being affected by supply i.e. clinicians may be less likely to refer when they are aware of prolonged delays.

In addition to considering how capacity of services needs to adapt to demand, it is worth considering how the model of care adopted for gender identity services may influence demand. Developments in the Scottish model of care may have the potential to reduce demand for specialist GIC services if more care is provided in community and primary care settings, or within existing secondary care settings in other health boards. Conversely, as services develop to provide greater support for trans people, for example in schools, more trans people may feel able to present to healthcare.

## **The Service User Experience**

Attendees at Scottish GICs between 2014 and 2016 provided a range of views on current services and how they felt this met their need. There was a consensus that waiting times were a key issue, with many describing in detail the consequences of long waits for initial assessment including worsening mental health and self-harm. It was expressed that the provision of some form of support while on the waiting list would be helpful in alleviating this, and that increased communication from GICs around how long they were likely to wait with signposting to other appropriate services including third sector initiatives and peer support groups in the interim would also be helpful. However, while this would be a way of improving the current situation, the main desire was for waiting times to decrease considerably. There was also an expression that waiting times between appointments were too long and lengthened the process of transition, particularly for those who were already decided on which treatment options they desired. Due to the long waiting times, the number of individuals who

already knew which treatment options they wanted on arrival at initial assessment appointment was fairly high, particularly for hormone therapy.

Frustration with long waiting times and delays in accessing treatment was reported to contribute to the perceived need to withhold information from GIC staff, which was another key theme. Around a third of all service users identified that they had withheld information on issues including their mental health, gender identity, and sexuality in order to avoid delaying treatment. It was highlighted in particular that open discussion of mental health problems was perceived to lead to prolonged delays:

*“So many people are held back from getting hormones or surgery due to poor mental health. This makes you feel like you can't speak about anything negative in your life because the appointments are so far apart any delays will just cause worse mental health problems.”*

The GRP describes that “if significant medical or mental health concerns are present, they must be reasonably well controlled” prior to initiation of treatment. It is clear that service users and service providers vary in their interpretation of this guidance, and more open dialogue about the precise requirements may be helpful in clarifying how well people must be. Given the potential that inability to access gender affirming treatments may worsen mental health problems (5), it is likely that there will need to be a balance based on clinical judgement for each individual, but explicitly involving service users in this decision may alleviate some of the desire to withhold information.

In relation to treatment, service users were generally very positive about all treatment options they had personally received. However, there were a mix of views expressed about the provision of information prior to undergoing treatment. In particular, service users expressed that they felt they would benefit from increased information on all available options for a treatment type, to allow them to come to an informed decision about what was best for them. Again, it was expressed that these decisions often felt rushed due to long period between appointments. In particular explanation of fertility preservation and surgical options was felt to be inadequate and inconsistent. Though this may be partially due to the fact that surgery is not provided in Scotland and so clinicians are not personally involved, service users strongly felt that more thorough explanation of all available alternatives would assist them in coming to decisions about their transition, in order to come to a position of true informed consent.

Overall service users appeared to support a person-centred, informed consent model of care. Good examples of practice were highlighted where clinicians had tailored the GRP to meet the needs of individuals, with it felt strongly that this helped validate and support the gender identity of trans people using services. It was felt that the GRP in its current format was fairly accessible, but that it represented a very binary view of gender identity, and this was in keeping with the finding that those who identified as non-binary were more likely to report negative experiences at GICs. Service users felt however that it would still be helpful, given that the GRP is the current national

guideline, if it were made available at GICs and openly discussed with patients, particularly where there may be any deviations for individuals to help explain why that might be.

### **Adherence to the Gender Reassignment Protocol**

The Scottish Gender Reassignment Protocol presents a clear vision and pathway for what services trans individuals should be able to access to facilitate their transition. In this assessment, based on interviews with stakeholders including service providers, it appears that Scottish GICs largely adhere to the GRP. There were a few instances where there were systematic deviations, for example that it is not possible to self-refer to Lothian GIC despite the protocol recommending this, and that it is usual Highland GIC practice to require a second opinion prior to beginning hormone treatment despite this not being required by the protocol. It would be worth considering whether these practices could be brought in line with the standards laid out in the guidance. It was also noted that in some locations e.g. NHS Lothian some aspects of GRP provision are being commissioned to the voluntary sector, and that this is working well to relieve pressures on specialist services. However, over and above this there was wider discussion within stakeholder interviews and service user questionnaires about the suitability of the GRP in its current format.

It was expressed that the current GRP is not as inclusive of non-binary individuals or supportive of a person-centred approach to treatment as it could be. The language and terminology is also now outdated. Moreover, the recent decision of the NGICNS to endorse the removal of the separate pathway for certain treatments through the Adult Exceptional Aesthetic Referral Protocol (AEARP) for reasons of equity make it likely the protocol would be required to be updated even in the absence of these concerns. Therefore, it seems appropriate to use this opportunity to revise the protocol to more accurately reflect the current landscape for trans people in Scotland.

### **Inequalities in Access to Services**

It has been highlighted that trans people are at risk of experiencing health inequalities, which stem from a range of factors including stigma, reduced healthcare access, and poorer social circumstances, whilst gender affirmation is seen as an important determinant of health(5)(57).

This assessment focused on inequalities with regards to access to healthcare services. The literature suggested difficulties for trans people in accessing healthcare, including in Scotland, with criticism of long waiting times, issues of rural access, and geographical variation in service provision(65). Interviews with stakeholders highlighted geography as an issue of concern, especially with regards to people from rural areas and travel costs, and these views were expressed most strongly by those working in boards without a local GIC and/or in more rural settings. The requirement of all individuals to travel to Sandyford for their second opinion for surgical assessment was also highlighted as a potential inequality. Several novel solutions were suggested to overcome this, such as increased access to telemedicine facilities or provision of

satellite clinics. However, the main recommendation by those with these concerns was for increased local provision of services, whether this be specialist gender service provision in these areas or facilitation by GICs of other local services (such as primary care or chaplaincy) to provide some of this care.

Potential access issues for people with other mental health disorders, people from more deprived backgrounds, people with learning or physical disabilities, and people from ethnic minority groups were also highlighted. Concerns were raised about access to services for young people, as Sandyford GIC is located in a sexual health setting that may be a daunting place for young people and their parents to attend, and also there is little option for individuals where their parents are unsupportive of their gender identity (particularly those who live far from the Sandyford). There was also a potential inequality in access identified by both service users and stakeholders for non-binary individuals, however some service providers felt that this may have improved more recently as services have developed their understanding of this population group.

Service data highlighted a potential socioeconomic gradient in referrals to Scottish GICs nationally, with higher proportions of referrals from adults and especially young people from more deprived areas. When broken down by area this was most marked in attendees at Sandyford GIC, and there was little evidence of a similar gradient for Lothian or Highland GIC. The existence of a socioeconomic gradient in presentation to trans healthcare services is in keeping with evidence from other populations, including the US(35)(58). A number of explanations could potentially account for this observation, including greater socioeconomic deprivation in the principal areas that GICs receive referrals from, an association between socioeconomic background and trans identities, or a greater need for support from people from more deprived areas. The fact that the distribution of individuals across health boards appears to be approximately as expected makes the first explanation less likely but does not exclude it, particularly as data from Grampian GIC were not available and it is one of the health boards with the smallest percentage of deprived areas(162). It is noted that these observations are based on NHS referral figures and do not include people seeking private care, which could influence the findings on people from less deprived areas, though it was felt by stakeholders that the proportion of patients accessing such services is likely very small. These are initial findings based on a limited set of data, and may warrant further investigation.

One potentially important aspect of inequalities in access to healthcare services that was not assessed in this report was that of stigma and discrimination. This issue has been reported in other settings and it would be important to assess it here, perhaps through further qualitative work with service users.

## **Models of Care**

A range of guidelines for trans healthcare and models of care were identified from around the world. The predominant guideline in use is that from WPATH, on which the Scottish GRP is based. Generally speaking, models of care identified were based on

the principles of individualised and flexible person-centred care, multidisciplinary approaches, shared decision-making, and taking a gender affirming approach. These principles appear to be consistent with the approach outlined in the WPATH guidance.

Some models of care were based on specialist clinics, whilst others emphasised delivery of care in primary care with support from specialists. The respective suitability of each of these approaches to Scotland merits further discussion, as other countries considered in comparative analysis have very different healthcare systems to Scotland. The importance of developing links with primary care and community services was emphasised during the interviews, and may provide an opportunity to further develop Scottish gender identity services to cope with increasing demand and the potential changing needs of the Scottish trans population. However, this HCNA did not specifically explore links with primary care, so this may be an important further piece of work.

This HCNA identified a range of reasons why further development of the model of care for gender identity services in Scotland would be worthwhile. This work could build on positive aspects of the existing services, whilst developing ideas to accommodate the potentially changing needs and wishes of the Scottish trans population. On the one hand, it was discussed that gender identity services were experiencing a good attendance rate with most referrals being appropriate. A multidisciplinary, person-centred approach with initial assessment followed by referral for further interventions based on need has been adopted in GICs where staffing levels allow this; this approach is consistent with the attributes of models of care outlined above. However, there were concerns related to the capacity and resilience of services, with long waiting times an issue, including once an individual is within the system. Further concerns were expressed about individuals feeling unable to express all of their needs and concerns, potentially saying what they think they need to in order to receive treatment due to concerns over waiting times and lack of flexibility in the care pathway. Related to this is the concerning finding that some trans people may be presenting to community services with severe mental health issues because of difficulties accessing specialist mental health services. Issues related to recruiting and maintaining a specialist workforce were also raised.

A range of suggestions was made as to how services could deal with increasing demand. These included increased education for generalists, expanded service capacity including increasing available accommodation at some sites, altering the care pathway to include pre-assessment or triage, or adopting another service model. With regards to the latter, models which included working more closely with community and local services were highlighted, particularly the potential of commissioning certain services from the voluntary sector such as specialist counselling and group work which can be difficult to provide within existing assessment clinics. Increased staffing was highlighted as being necessary to cope with the increase in demand, with one option being the addition of nursing staff and nurse-led services as it was suggested this would both widen the multi-disciplinary team and overcome recruitment issues.

Additionally, establishing and maintaining links with professionals in other areas e.g. CAMHS, schools (including educational psychologists) could aid in capacity building. Other suggestions relating to how services could address inequalities in access to services have been highlighted above, and include increased formal support for those on waiting lists, consideration of centralising commissioning of services which are inequitably distributed such as hair removal, and provision of additional gender services locally.

Further developing the models of care used locally and nationally could address a number of the issues found in this HCNA, and is central to addressing the initial question of how to plan for increased demand for services at local GIC level. The principles outlined above, including individualised and flexible approaches linked to primary care with a focus on informed consent, could be a potential option. Approaches such as this would be consistent with the views and preferences of specialists working in this field, and could help to address issues of capacity in the long-term by working more closely with primary care and community services including the third sector. Offering increasingly individualised and flexible care could help services adapt to the potentially changing healthcare needs of the population.

### **Scope of this HCNA**

This HCNA explored the evidence available regarding prevalence of trans identities, the mapping of current service provision to need, and potential future demand for gender identity services. Evidence to inform planning of these services is limited, but potential scenarios have been discussed. An implication of the evolving situation regarding increased demand for gender identity services, changes in the population presenting to services, and the potential explanations for this, is that the model of care adopted in gender identity services may benefit from further development.

This assessment was principally focused on exploring the increased demand for gender identity services in Scotland. From a public health perspective, it is important to consider the interrelationships between need for healthcare, demand for healthcare, and supply of healthcare. Many of the issues discussed here may be related to the relationship between supply and demand, for example that increased service provision can lead to greater demand for healthcare. The nature of this assessment means that it is more difficult to draw conclusions on the wider question of healthcare needs among the local trans population. The increase in demand for services may indicate an unmet need in this population and may have been triggered by increased awareness, acceptance, and understanding of trans identities. However, it is likely that there are aspects of healthcare need that have not been identified here. Doing this would require a different approach and methodology, including engaging with the wider trans population, especially those who are not in contact with health services, to develop a more in-depth understanding of their needs.

## What Does This Mean For Us?

While there is no precise estimate of the size of the trans population in Scotland, it is clear that the proportion of trans people choosing to present to NHS and third sector services is increasing. This is positive, as it allows more people access to gender-affirming treatments, but has increased pressure on services and led to long waiting times. These waiting times impact negatively on service users and patient-clinician relationships, and must be reduced. While the increase may be reaching a plateau, there is still significant progress required to catch up with and maintain existing demand.

Additionally, the characteristics of those accessing services is changing, and may not be met by current services. More young, questioning, and non-binary people are presenting who may have differing requirements and expectations of services, requiring them to adapt their approach. The current national protocol was not felt to support an inclusive, person-centred approach to support for trans people, which may disadvantage those with non-binary gender identities. There are other potential inequalities in accessing services, particularly relating to geography, with a minority of Scottish health boards providing local gender identity services and third sector services also largely based in urban centres.

There was no consensus among service providers on the best way to reshape services to better match the changing needs of the trans population. It is likely that detailed consultation with stakeholders, with a strong focus on service user views, is required to design services which are acceptable and appropriate for all Scottish trans people.

## Chapter 7: Conclusions and Recommendations

This HCNA aimed to explore evidence that would inform planning of future capacity and models of care in Scottish gender identity services. Evidence on the underlying prevalence of trans identities was limited in terms of its ability to provide accurate estimates to inform healthcare planning, though broad estimates of national prevalence could be made. Consistent evidence was found of an increased demand for gender identity services locally, nationally, and internationally, with a range of potential complex explanations.

Future projections of demand for gender identity services were not identified from other sources, but national service usage data are potentially useful in informing the likely trajectory. Three potential scenarios were discussed, of which the most likely appears to be a plateau in referral numbers, potentially at some point in the near future. However, this is an evolving situation from which it is difficult to make predictions, except that changes are likely to continue and services will need to be flexible enough to adapt.

A key finding of this HCNA is that whilst there is increasing demand for gender identity services, there is also evidence that the population seeking services may be changing. This means that whilst services need to adapt to increases in demand, they may also need to change to accommodate people with different healthcare needs. As a result, any changes in workforce capacity should be carried out alongside consideration of developing the model of care currently used, in order to adapt to this evolving situation.

A variety of positive aspects of the current gender identity services were highlighted, alongside a number of limitations, including a range of potential sources of inequalities in access to services, a potential lack of flexibility in adapting care pathways to patient preference and gender identity, and inconsistency in service provision nationally. This variation has the potential to disadvantage some service users, and is inconsistent with the Realistic Medicine approach laid out by the Scottish Chief Medical Officer: that the person receiving care should be at the centre of the decision-making process, with an exploration of personal goals and a realistic discussion of the potential benefits and risks of all treatment options(163). Updating the model of care used in gender identity services and using innovative approaches to reduce inequalities and variation as recommended below could help bring services more in line with this approach. It is essential to involve the trans community in such discussions, to deliver better, more responsive services and better outcomes through community engagement and empowerment(164).

Ongoing data collection is likely to be essential in informing any planned changes, and in monitoring their impact. It is acknowledged that this HCNA focused on provision of specialist healthcare services, with service user data coming only from trans people who already engage with these services – this will not encompass the totality of health

or social needs of the trans population in Scotland, and further work with the community is essential to expand our knowledge of these wider needs.

Where possible, the below recommendations identify the group(s) who would be most appropriate to action them. Recommendations 1-8 focus on immediate steps necessary to reconsider models of care for gender identity services and reduce inequalities in access, and will require engagement with the trans community in order to shape services according to their diverse needs. It is our hope that this could be led by and build on the work already undertaken by the NGICNS, possibly through stakeholder events after initial consideration of the recommendations by the group.

Recommendations 9-13 focus on areas which will need to be considered and actioned in the longer term, to ensure that gender identity services in Scotland remain sustainable and appropriate for the needs of the trans community in the future.

## Recommendations

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| <p>1. Consider alternative models of care for gender identity services to support the development of multidisciplinary, person-centred approaches which reduce variation, including the potential for:</p> <ul style="list-style-type: none"><li>a. Additional local provision of both specialist and support services within the NHS</li><li>b. Additional involvement of primary care services</li><li>c. Additional involvement of community and voluntary sector in service provision</li><li>d. Centralised commissioning of additional services e.g. hair removal.</li></ul>   | <p>NGICNS<br/>Local GICs<br/>NHS Boards<sup>2</sup><br/>3<sup>rd</sup> Sector<br/>NSD</p> |
| <p>2. Ensure gender identity services are adaptable to changes in the trans population presenting to GICs e.g. increasing numbers of non-binary people, those exploring their gender identity, and younger patients, for example through:</p> <ul style="list-style-type: none"><li>a. Ensuring equality of access to services for non-binary individuals</li><li>b. Offering non-assessment focused services within GICs e.g. separate exploratory space to discuss gender identity and treatment goals</li><li>c. Resourcing of third sector organisations to work with those in the early stages of questioning or exploring their gender identity</li><li>d. Access to email/online support.</li></ul> | <p>NGICNS<br/>Local GICs<br/>3<sup>rd</sup> Sector</p>                                    |

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<sup>2</sup> References to 'NHS Boards' would include, where relevant, representatives from primary care e.g. Local Medical Committees, primary care contracting

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| <p>3. Increase the support which is available to individuals on waiting lists for GICs, through greater partnership work including signposting to voluntary sector and community support, increased communication about likely waiting time, provision of interim NHS services where possible, and advice on potential risks of self-medication</p>  | <p>NGICNS<br/>Local GICs<br/>3<sup>rd</sup> Sector<br/>NHS boards</p> |
| <p>4. Consider short-term increases in staffing capacity to assist in decreasing waiting times, for example through the expansion of nursing care as in Lothian GIC where waiting times have fallen.</p>   | <p>Local GICs<br/>NHS Boards</p>                                      |
| <p>5. Take steps to address geographical inequalities in accessing services through:</p> <ul style="list-style-type: none"> <li>a. Provision of alternatives to travel e.g. telemedicine, satellite clinics</li> <li>b. Increased communication of GICs with local NHS boards about patients attending to facilitate local assistance where possible e.g. phlebotomy, counselling, endocrine support</li> <li>c. Consideration of establishing additional GICs or other dedicated services e.g. as in NHS Tayside ‘hub and spokes’ model</li> <li>d. Increase provision of community support to ensure this is more widely available to trans people across Scotland.</li> </ul> | <p>NGICNS<br/>Local GICs<br/>NHS Boards<br/>3<sup>rd</sup> Sector</p> |
| <p>6. Take steps to address other identified potential inequalities:</p> <ul style="list-style-type: none"> <li>a. Ensure those with pre-existing mental health problems are not disadvantaged in accessing treatment</li> <li>b. Ensure services are accessible, appropriate for and acceptable to those with all gender identities, including non-binary individuals</li> <li>c. Ensure services are accessible to those with physical and learning disabilities</li> <li>d. Ensure services are accessible to those with poor literacy e.g. not relying on online/printed information.</li> </ul>   | <p>Local GICs</p>   |
| <p>7. Ensure that clinicians at GICs are adequately supporting the informed consent model by providing detailed information on all available treatment options, with subsequent decisions being led by the wishes and treatment goals of the individual.</p>   | <p>Local GICs</p>   |
| <p>8. Strengthen collaboration to ensure services meet the needs of the trans population, including wider healthcare and support needs, by involving trans people, third sector organisations and community</p>  | <p>NGICNS<br/>Local GICs<br/>3<sup>rd</sup> Sector</p>                |

groups in the planning and development of gender identity services as described in recommendations 1-7.

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| 9. Continue workforce development efforts to expand specialist workforce and support workforce including: <ul style="list-style-type: none"><li>a. Development of further training programs for specialist, generalist primary care and mental health staff</li><li>b. Development of links with other sectors to enhance multi-disciplinary working and share resources e.g. education, social care.</li></ul>   | NGICNS<br>NHS Boards<br>NES <sup>3</sup>              |
| 10. Develop national standards for what is required to be established as a Gender Identity Clinic.  | NGICNS  |
| 11. Increase data gathering on the trans population and from GICs to assist with monitoring inequalities and for research purposes. From GICs, this should include as minimum dataset components: <ul style="list-style-type: none"><li>a. Number of referrals</li><li>b. Age at referral</li><li>c. Gender identity</li><li>d. Ethnicity</li><li>e. Health board of residence</li><li>f. Waiting times</li><li>g. Treatments undergone</li><li>h. Outcome of treatment</li><li>i. Service user satisfaction.</li></ul> | NGICNS<br>Local GICs<br>3 <sup>rd</sup> Sector<br>ISD |
| 12. Revise the Scottish Gender Reassignment Protocol to more accurately reflect current practice: <ul style="list-style-type: none"><li>a. Remove reference to the AEARP</li><li>b. Make the adoption of the informed consent model by GICs explicit</li><li>c. Make clear that choosing different treatment options is possible and non-binary outcomes are equally valid.</li></ul>   | Scottish<br>Government                                |
| 13. Explore the development of gender reassignment surgical provision in Scotland.  | NSD   |
| 14. Circulate this HCNA to all relevant partners to ensure recommendations are enacted, including NGICNS and Scottish Directors of Public Health  | ScotPHN   |

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<sup>3</sup> NHS Education for Scotland

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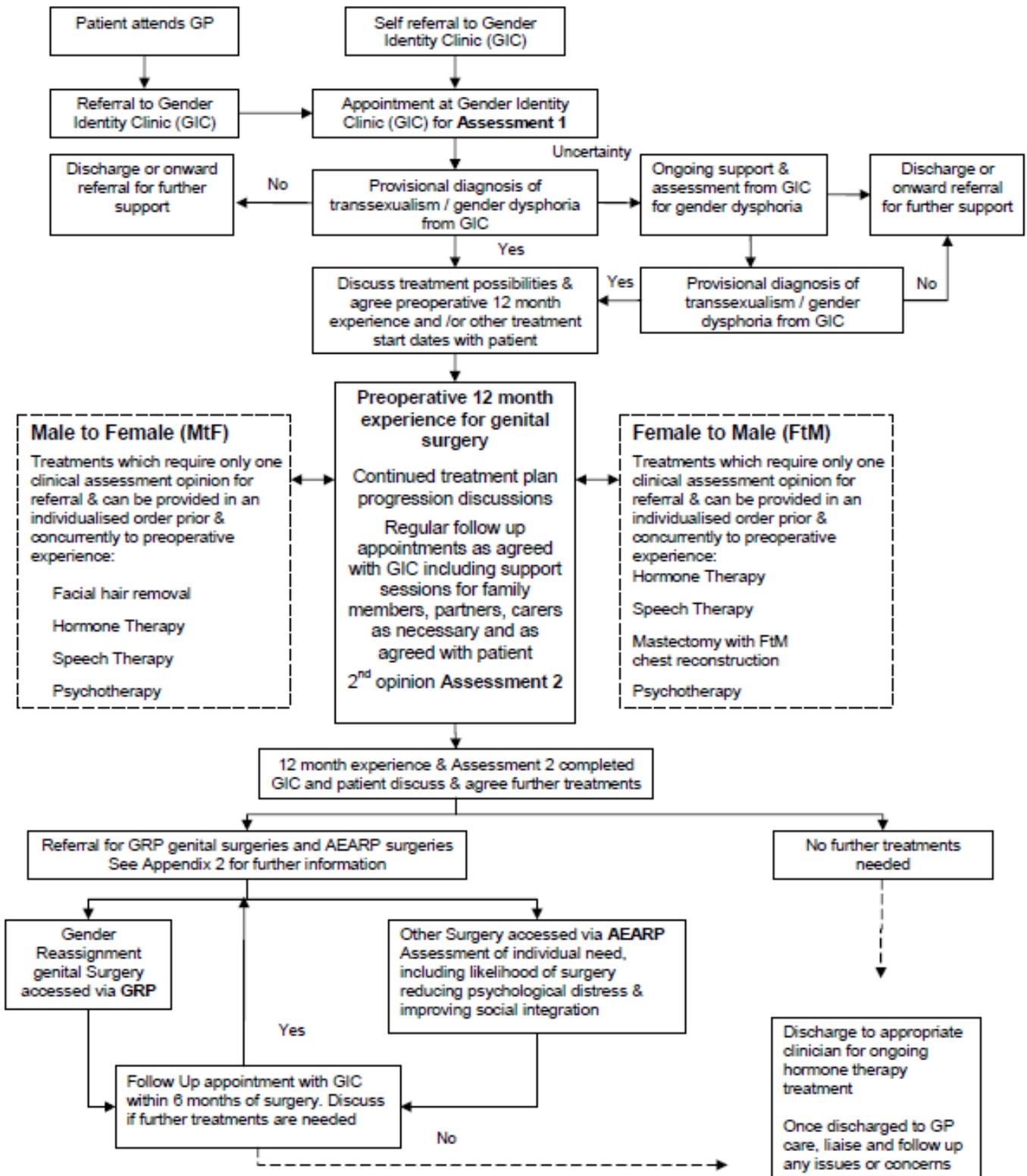
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# Appendix 1 - Gender Reassignment Protocol

When implementing the protocol, the patient should be a full participant in decisions about their healthcare and wellbeing and be given any information or support that they need in order to do so.



Excerpt from NHS Scotland Gender Reassignment Protocol (2012)



r e p o r t

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