



A report about the experiences, views and opinions of people using Gender Identity services in England.

February 2016

## Contents

|   |    |
|---|----|
| Intended Audience.....  | 4  |
| Introduction .....  | 5  |
| What is happening at a national level?.....                                 | 5  |
| Factors which influence perception of quality .....                         | 6  |
| General Overview .....  | 7  |
| Key aspects of service delivery .....                                       | 8  |
| Gender Identity Service provision in England .....                          | 8  |
| Summary of recommendations .....  | 9  |
| Who answered our questions? .....   | 10 |
| Recurring Themes:.....  | 12 |
| Experiences of transition: getting help and starting the journey .....      | 13 |
| Being a “Smart Patient”: finding information. ....                          | 14 |
| Patient information: good practice by local Healthwatch Organisations ..... | 15 |
| Recommendation 1: Equality and diversity .....                              | 16 |
| Relationships with the GP .....   | 17 |
| Incorrect guidance on NHS Choices.....                                      | 18 |
| Statement from NHS England about NHS Choices .....                          | 19 |
| Recommendation 2: Information.....  | 19 |
| GPs: What works well .....  | 20 |
| Satisfied patients or grateful recipients? .....                            | 20 |
| GPs: What didn’t work so well.....  | 21 |
| What can GPs do to improve?.....  | 22 |
| Patient centred practices .....   | 22 |
| Referrals from the GP: waiting and travelling.....                          | 23 |
| Waiting.....  | 23 |
| Recommendation 3: Communication .....                                       | 24 |
| Travelling.....   | 24 |
| Recommendation 4: Travel costs .....  | 25 |
| Hair Reduction.....   | 25 |
| Recommendation 5: Hair reduction .....                                      | 26 |
| Medication.....   | 26 |
| Recommendation 6: Access .....  | 28 |
| Other treatment.....  | 28 |

|  |    |
|--|----|
| Surgery .....  | 28 |
| Conclusion .....   | 29 |
| Appendix 1: Charts .....   | 31 |
| Appendix 2: Response from Devon Partnership Trust (Laurels Senior Management team) ..... | 40 |
| Appendix 3: Response from South Devon and Torbay Clinical Commissioning Group .....      | 42 |

We would like to thank...

Local Healthwatch organisations Plymouth, Torbay, Cornwall, Bristol, and Southwark for helping to promote this work via their networks, as well as Healthwatch England for their support. We also worked with the Diversity Trust, and the LGBT Foundation which enabled more people to get involved, and all our twitter and facebook friends. Our volunteer helpers and advocates proved invaluable to this project and we extend our sincere thanks, you know who you are!



## Intended Audience

- Relevant Commissioners and Providers of Gender Identity Services
- Patients, users of social care and the wider public.

This report has been prepared in accordance with s221 of the Local Government and Public Involvement Act 2007.

## Introduction

*“I know [my personal] submission is a bit light on details, **but it is real**. It's an attempt to register a presence in the system from people like me who are otherwise invisible in the statistics. My problem with the system is upstream from you. Until the very specific detriment of neither having my gender legally recognised, nor being legally protected from discrimination, I am too scared to even start to transition because I have too much to lose - I have a family to support. They love me for who I am, but I can't really **be myself** for fear of letting them down. On the plus side, I have been to the GP (& one ENT clinic) for non-gender related things, presenting significantly non-standard - a guy with long hair and some jewellery in a skirt and tights - and they've been perfectly okay about it.”*

Woman, living in role for 14 months, aged 40 - 49

This report contains descriptions by 149 people who were (and are) seeking help for gender identity issues. Their perceptions, experiences and views are discussed about outcomes of care and treatment quality. We did this work to complement the work being carried out by NHS England, and we have heard locally in Devon about long waiting times and problems accessing treatment.

We intend, as a result of this survey, to help increase participation in better decision making about services, by providing recommendations based on what people told us, to help to enable and inform:

- on a personal level, for readers seeking help and the professionals involved
- locally with commissioners and providers
- strategically in planning and delivering services

## What is happening at a national level?

*“In 2012/13, NHS England’s Clinical Reference Groups (CRGs) were asked to develop a number of draft service specifications and commissioning policies, to support the nationally consistent commissioning of specialised services across the country. These service specifications and commissioning policies were subject to a short public consultation. Feedback received during this consultation was used to further develop the specifications and policies for use in contracting with providers. NHS England was unable to recommend adoption of the specifications and commissioning policies developed by the former Gender Services CRG (2012-13) because of the volume of feedback received in relation to those documents, in particular relating to equality and equity of access issues.”<sup>1</sup>*

The work of the Gender Services Clinical Reference Group is ongoing and we hope by this report to help further inform policy development from the point of view of the consumer. We did this work as a result of involvement in some of the task group and symposium<sup>2</sup> work being carried out by NHS England<sup>3</sup>, and in response to a “call-out” for evidence and case studies by Healthwatch England to the network of local Healthwatch Organisations.

Healthwatch England raised concerns<sup>4</sup> with NHS England over Gender Identity Services, based on the feedback from around the local Healthwatch network. This initial feedback showed that sometimes the help that people need is not there.

Healthwatch England's findings, in brief, were as follows:

- Waiting times for operations, which should be less than 18 weeks, are sometimes as much as 21 months.
- Demand for services for transgender people is increasing each year - but there are not enough specialist services to cope.
- Communication with patients is poor, leaving people who are waiting for help unsure as to when they might get it

We aimed to tackle some of these questions and offer more people the chance to share their views in our survey. During the drafting of this report the cross parliamentary report was published about Transgender Equality<sup>5</sup> and we have made reference to the NHS section throughout our report. Our findings about the quality of service provision echoed the parliamentary report regarding the NHS.

The cross-parliamentary inquiry into transgender equality, according to the Guardian newspaper, found that the NHS was “failing in its legal duty in providing equal access to services.”<sup>6</sup> A “root and branch” review of the service is called for by parliament, and we hope that this report and our findings will help provide useful insights about the patient journey. The parliamentary report sadly found that:

*“the NHS is letting down trans people, with too much evidence of an approach that can be said to be discriminatory and in breach of the Equality Act.”<sup>7</sup>*

Our feedback showed this to be true in too many cases.

*“This is not a safe or fair system, and I suspect many of the most vulnerable patients, who don't know the procedures and don't know who to ask for advice, end up falling between the cracks, with significant detriment to their mental health and wider lives.”*

(trans person aged 40 - 49)

## Factors which influence perception of quality

The American Advisory Company<sup>8</sup> cites 5 factors that influence patient perception of quality, from an article in the Journal of Clinical Oncology<sup>9</sup>. 374 patients were studied, and compared their perception of their care quality with their provider's adherence to evidence-based guidelines. The key factors which influenced their perception of quality were:

- Ability to identify which physician to go to with questions or concerns
- Positive communication with physician about treatment decision making
- Positive communication with ancillary staff

- Trust in the physician
- Trust in the health care system

It is worth bearing these factors in mind when reading through the stories and comments we received from 149 people across England during the autumn of 2015.

## General Overview

In Devon the Gender Identity Clinic is provided by Devon Partnership Trust, commissioned by NHS England. We have had a response from the Laurels ([see appendix 2](#)) and we will be ensuring via NHS England that other clinics mentioned in the data will be offered the chance to hear what people have said to us.

We have also had a response from one of our local Clinical Commissioning Groups which asked us to clearly state the relationship between provider and commissioner ([see appendix 3](#)). NHS England is responsible for ensuring the effective commissioning of gender identity clinics across England. The authors of this report are meeting with the NHS England clinical task and finish group in May 2016 to discuss the findings. Keep up to date with the task and finish group with [this blog](#)<sup>10</sup> from Will Huxter (group chair).

In many cases, our respondents found that local community groups and social networks were very useful and practical sources of support and information that greatly complemented that which the NHS currently offers.

We received comments relating to most of the provision across England and will be sharing this anonymised information in more detail with relevant providers and commissioners.

The responses came in via our social media channels following an extensive twitter campaign. Several acknowledged partners joined us along the way which helped boost the social media profile.

This naturally means that the responses to seeking information will be incontrovertibly skewed towards those who are willing and able to use the internet; nevertheless it was clear that people valued this opportunity to share their stories.

We expected a diverse range of views but were pleasantly surprised at the amount of people who completed this survey<sup>11</sup>. We hope that we have given a good indication of the key aspects of the journey travelled by our contributors. The treatment journey takes years to complete. People can take years to feel ready and able to go and see their GP and get help. And, some people talked about starting their journey 20, 30 or 40 years ago. Times were very different then. It is arguably testament to the forthrightness and persistence of previous generations that today's younger people have simpler access to Gender Identity services. From what people of all ages have told us, however, there is still a long way to go to ensure equitable access and treatment.



The “smart patient” is a person who finds reliable information and uses it to improve treatment and make “better doctors”. Information gathering and the quality of what is garnered by those seeking help is certainly a feature of a lot of the feedback we received; people felt that their health professionals and administrative staff ought to possess far more awareness of transgender and non-binary culture and treatment pathways than they already do.

## Key aspects of service delivery

The role of a trusted and supportive GP during initial consultation and through excessive waiting times is crucial. We received lots of mixed reviews concerning this facet of case management. We know that when this relationship breaks down the impact can affect the entire perception of the treatment process.

People had made multiple trips of hundreds of miles and we found they may not have been reimbursed according to their entitlement, in many cases.

People also talked about hormone therapy, laser and electrolysis and other treatments and from what we have been told, there does not seem to be a standard and equitable delivery of these types of services. This may be due to treatment for some being accessed prior the interim guidelines issued in 2013, although even since then there is a waiting list for funding and the protocol does not appear to be implemented in a fair way.

Not everyone who contacted us had been through surgery. Those who had were pleased, in the main, with the results. There were mixed reviews about post-operative care. The waiting times were considerable for all aspects of provision and at each stage of referral.

We have attached appendices with various charts and graphs relating to our feedback.

## Gender Identity Service provision in England

The patient, having been referred from a GP or other specialist service can access one of

*“...7 gender specialist clinics for adults in NHS England and referrals can be made to these clinics to explore with the patient the options available to them”<sup>12</sup> -*

You can find information on clinic location, assessments, referral and treatment in the interim Gender Dysphoria Protocol and Service Guideline 2013/14, which we have referred to in this document. There is information on the NHS Choices website<sup>13</sup> -the caveat being that during the preparation of this report we found that information in the section “How to find an NHS Gender Identity Clinic” (regarding current referral and diagnostic practice) was not up to date.

## Summary of recommendations

### Recommendation 1: Equality and diversity

There are existing initiatives for training and support for health and care professionals to increase their awareness, some of which have been developed by Local Healthwatch and Trans advocacy organisations. We welcome this and hope that more general practice physicians in particular will take an interest and become Gender Identity champions in their localities. We recommend that as a result of increased awareness of the needs of people seeking help about gender identity issues, GPs, their staff and other community groups will encourage more access to information sources that are clear, easy to understand and concise, particularly around treatment pathways.

### Recommendation 2: Information

If independent sites are using the NHS information standard or have other reputable accreditation it may be helpful to clearly display this so that people know they are accessing good quality and trustworthy information from a publicly accountable source. The interim Gender Dysphoria Protocol<sup>14</sup> is in the public domain and on page 6 of that document you can view the Protocol Flow Chart. However, despite the presence of the NHS information standard quality mark, it is not referenced on NHS Choices. This should be rectified as soon as possible. Then, GPs and other service providers would know to make the protocol available to patients to help guide them. Perhaps GPs and other service providers would feel more confident and encouraged to give this information to patients seeking treatment.

### Recommendation 3: Communication

Communication from GP, clinic and surgical ward needs to be positive and proactive, not only about treatment and decision making, but to ensure individual information needs are met during referral and waiting times i.e. “how long is the list”, “how far am I down it?”

### Recommendation 4: Travel costs

In line with the recommendations from Healthwatch Islington, providers (GPs and clinics) need to be supported to ensure people are able to access the Healthcare Travel Costs Scheme<sup>15</sup>.

### Recommendation 5: Hair removal

If people have been unable to access NHS funded electrolysis or laser hair removal prior to 2013, this should be offered to them now in a timely and effective fashion, if it is a desired option at their stage of treatment. NHS England recommends that “facial hair removal should commence prior to social gender role transition, as the



beard must grow to visible lengths to be removed.” There are plenty of electrolysis providers, why are people having to wait for a year?

### Recommendation 6: Access

Waiting times and access to essential non-invasive procedures in the meantime, such as hair removal, and medication simply must be improved to reduce the anguish and risk that can be associated with such lengthy periods between assessment and surgery in particular.

## Who answered our questions?

The transgender, and non binary community, like other communities and groups, is not homogeneous, it is complex and individuated. We adopted an understanding which is exemplified below.

*‘By “Trans / Transgender” we are referring to all people who consider themselves to fall under the trans / transgender and gender variant umbrella. This includes, but is not limited to: Cross-dressing & transvestite people, trans women, trans men, transsexual men & transsexual women, people identifying as androgyne, polygender, genderqueer, gender non-conforming, dual gendered, & non-gender identifying, gender questioning people, gender variant & gender diverse people, transgender people & intersex people and anyone who feels that the gender assigned to them at birth incompletely describes or does not at all describe their own personal gender or non-gender identity.’*

Transgender Resource and Empowerment Centre website (in Manchester, serving the North-West.)<sup>16</sup>

Some people prefer to self-define their gender status. We also chose a few well used indicators. The majority of respondents to this question identified themselves using these indicators. Most were women, nearly 1/4 were men and just under 1/5 identified as non-binary. 2 people identified as intersex.

A further 16 people chose different identifiers, e.g. “agender” “non gendered” “demi-boy, queer”.

1 person from the 16 who chose to define differently told us:

*“I am a non-binary trans person and also have an intersex condition. Like most intersex people, I don’t consider my intersex status to be part of my gender, as being intersex is to do with the specific reproductive and chromosomal characteristics I was born with and my gender is to do with my internal sense of who I am, so the two are completely different and are not mutually exclusive”*  
(Non binary trans person aged 21-29)

The answers we received demonstrated the diversity that exists within the community of trans and non-binary people, reflecting the need for a highly personalised and sensitive approach to commissioning and providing services. Non binary people particularly felt that there was not enough understanding about their identity.

Many people had high praise for parts of the service they had received, but equally, a lot of people were angry about insensitive communications, perpetual cultural misunderstandings, prejudice and misgendering.

We recorded a broad distribution in the age range - from younger than 18 to older than 60, with many different accounts of their life journey. The majority of respondents were in the 3 age brackets of 40 or over. (see chart "Q2" in the appendix).

Just over 1/2 the respondents are currently in transition, with 50 people going from man to woman, or "towards feminine" as 1 respondent suggested. A further 23 people are transitioning from woman to man, (towards masculine) with 10 people identifying as non-binary and in transition. Approximately 1/3 of people have completed their transition, and 3/4 of these respondents were man to woman, 1/5 woman to man and just under 1/20 were non binary.

We asked about income levels because:

- We had heard, prior to this survey, time and time again from people about the costs associated with travel to secondary care
- We wanted to ascertain how well people were assisted and supported to access services that were, in many cases, a considerable distance from their home.

Chart "Q11" in the appendix shows that most of our respondents to this question had an income of less than £19,000. 56 people were either unwaged or on benefits, or had an income of less than £10,000.

Chart "Q9" shows that most people didn't get advice or support regarding travel costs. Had advice and support for each of those respondents who answered no, and who were eligible, been available at the right time, this might have led to reimbursement under the Healthcare Travel Costs Scheme.

The responses are varied on issues like waiting times; there are long waits of sometimes over a year to get to the first psychotherapeutic referral appointment. Funding seems to be an issue as well as availability of trained clinical staff to perform surgery.

CCG's are perceived as another stumbling block, with funding for medication or intermediate treatment being delayed or refused.

## Recurring Themes:

“Bureaucratic mismanagement”

- ☹️ *Letters not being sent out in time, muddled staff filing systems, overburdened administration teams*

“Staff shortages”

- ☹️ *Not enough surgeons*

“Waiting times”

- ☹️ *Perceived to be a result of the poor administration system coupled with inadequate staffing levels when compared to demand for services*

“Communication/ information”

- ☹️ *The information provided by the NHS is not up to date*
- 😊 *Good GPs supported their patients throughout the process*
- ☹️ *People often felt abandoned or lost*
- 😊 *A mix of communication and information methods is preferred (peer support and clinical staff)*

“Needs led/patient led services”

- ☹️ *Shortcomings gave an overwhelming sense that the service is not built around patient need and preference*
- ☹️ *Hormone therapy and other treatments were withheld by GPs*

“Clinicians, other health professionals and support staff - awareness of trans issues (i.e. anti discriminatory training needs in many cases)”

- ☹️ *There is a lack of understanding about the rights and status of trans people at all levels of service delivery and in all areas, even the surgical wards*
- ☹️ *GPs in particular were heavily criticised for their lack of understanding about trans issues*

“Clinicians, other health professionals and support staff - attitudes towards people seeking help”

- ☹️ *Some staff had demonstrated very ignorant and prejudiced behaviour towards people seeking help*

## Experiences of transition: getting help and starting the journey

*“Ever since I transitioned I seem to have been blessed by good GP’s - but that may be because I have always “interviewed” them before signing up with them!”*  
(woman aged over 60 years)

45 people recounted their initial experience of seeking help, some very briefly indeed. Obviously those who are currently in transition are at various stages of the process, from “living in role for 14 months” to just at the point of reconstruction surgery.

One woman respondent, planning to transition, in the 50-59 age band had delayed the full process for more than 10 years...

*“...while my children were growing up. My [now grown up] children are fully aware of and supportive of my intention and I have support from other family members.”*

This person was, in 2001, “simply referred on to the local mental health team” without being told anything about further referral or treatment options.

She also told us:

*“I then had a cursory discussion with a psychiatrist, who claimed experience of transgender issues, but clearly knew next to nothing about them. On the basis of a 15 minute discussion he concluded that no further support should be provided because 1) I had maintained a married relationship for a period of years and 2) I had children - so no problem. I was provided with no support, despite the fact that I had had a mental breakdown immediately prior to seeking referral. I then arranged for what turned out to be a long period (3 years) of psychotherapy which I paid for entirely myself.”*  
(woman aged 50 - 59)

She has grown more informed about her options having been in touch with a local support group in the South West of England, Transfigurations in Torbay, which she praises highly. She is optimistic about her new GP. Although her initial experience was 15 years ago, we have specifically quoted this story to hopefully show how the availability and quality of help and support with gender identity issues have evolved in the meantime. She says that

*“Although I don’t know much about the budget for the GIS [gender identity service], my impression so far (based on a lot of discussion with service users) is that a phenomenal amount is achieved on very limited resources, especially because of the effectiveness of transgender support networks.”*

## Being a “Smart Patient”: finding information.

For many, whether having done some prior research - or not - the GP was the first port of call and they were very frequently mentioned by people.

The term “Smart Patient” was coined by Drs Mehmet C Oz and Michael Roizen in their book “You: The Smart Patient: An Insider’s Handbook for Getting the Best Treatment”

*“it was the kind of medicine we had always dreamed of practising ... in which patients realised the awesome power they had in controlling their own quality of care...they weren’t afraid to use that power to make us better doctors [author’s emphasis]...the best of those patients emerged like golden beacons... we referred to them by a highly scientific medical term that suited them best and still does: Smart Patients. We started to see them come into our offices...[they] began talking about this contraption they found called the internet...learning more in an hour than we remembered after eight years of medical school and residency.”<sup>17</sup>*

We asked people about their information seeking behaviour. Most people answered the question about finding information. Most people selected 3 or more information sources from the predefined choices. The 3 most prevalent were:

- The GP
- Transgender support groups
- Google

followed by dedicated websites, family and friends and other social media like facebook or twitter. Most of the information they found was deemed “helpful” or “really helpful”. Knowing where to go for information, questions or concerns is an identifiable quality marker<sup>18</sup>.

The emphasis on the web is to be expected as this was an online survey carried out using social media, therefore respondents may be predisposed to seek information online; for instance, although we were prepared to post out hard copies no requests for this were received.

Our respondents often spent a considerable period of time, sometimes years, thinking and in many cases, anguishing, about their circumstances, talking to people and researching their options, before they approached their GP.

*“Via search engines, found sites that reflected my own situation, then engaged with specialist websites/forums and started attending a number of Transgender Support groups (each one being quite a distance from my home address). Then after about 9 months, spoke to my GP due to anxiety and stress issues (coming out as being on the Transgender spectrum) After another year (4 months ago) approached GP with specific requirement to address my gender issues.”*  
(Non binary respondent aged 50-59)

It is no wonder people can feel disempowered by what may seem an inexperienced GP response, having looked into the information so thoroughly themselves. Positive communication with one's physician about treatment decision making is another key factor which may be said to influence the perception of quality.<sup>19</sup> Having access to the right, trusted information about pathways and treatment options is important to enable good shared decision making.

*"I was the one providing up to date information to my GP, rather than the other way round...after furnishing my GP with documentation and advising them to contact the GIC for further guidance on how to refer and the funding processes involved."*

(Man aged 18-20)

These days one is encouraged to research their condition prior to visiting the GP, so GPs need to be prepared, as Oz and Roizen found, for clued up "smart" patients, and welcome them.

## Patient information: good practice by local Healthwatch Organisations

Healthwatch Hampshire have co - produced an information video for adults<sup>20</sup> as well as information leaflets and a feedback report into the experiences of transgender and non binary people in Hampshire.

Healthwatch Devon has worked with young people to produce their "Made of Rainbows" film.<sup>21</sup> This film describes the experiences of young LGBT people growing up in Devon. They talk about their experiences of coming out as lesbian, gay, bisexual or transgender. They explore the effects on their mental and emotional wellbeing, and talk frankly about how it feels to try to get help from the health services.

During the course of writing this report we visited the Laurels clinic in Devon for an informal conversation and we would like, as a result, to work closely with the clinic to enable improvements to be made regarding information and signposting to entitlements, rights and advice that could be made available to people seeking help as well as GPs and other health and social care professionals.

We also spoke to the Diversity Trust and in Devon we are replicating their successful training events which have been held across the South West in partnership with local Healthwatch organisations.

We will share any results and learning points that may arise from our activity with local Healthwatch organisations across England. We would like to encourage other Gender Identity clinics to work with Healthwatch.



## Recommendation 1: Equality and diversity

There are existing initiatives for training and support for health and care professionals to increase their awareness, some of which have been developed by Local Healthwatch and Trans advocacy organisations. We welcome this and hope that more general practice physicians in particular will take an interest and become Gender Identity champions in their localities. We recommend that as a result of increased awareness of the needs of people seeking help about gender identity issues, GPs, their staff and other community groups will encourage more access to information sources that are clear, easy to understand and concise, particularly around treatment pathways.

*“Online information sites and support groups helped me to learn more about gender, better understand myself, and develop a vocabulary to describe my experiences. I did not realise that medical interventions were available to low income people in the UK until a trans friend told me about GICs. I found a local support group via online searches, and this support group has literally been a life saver when humiliating GIC ‘assessments’, bullying, and deliberate delays destroyed my mental health, and has been an invaluable source of reliable information including first-hand experiences. The NHS, including my GIC, have provided no useful or reliable information to me, but insisted on working on the assumption that I understood nothing about my gender and must undergo a long series of tests from several members of staff who are supposed to understand better than me what is best despite no real understanding of me or my life, and that introducing deliberate waits for treatment would somehow help me be less likely to regret the decision I’d made clearly and in a well-informed manner a year before I even got to the GIC.”*

(non binary person aged 30 - 39)

Online information led many people into face to face support groups, which were described by one person as “helpful and life affirming”, and that person now has a good support network.

One person got a lot of information from the social media site Tumblr and said

*“the NHS needs to have more-searchable (and correct) information. Since I began looking, there have been some good networks for trans resources, but they’ve all been done by private individuals. Get on it!”*

(demi-boy, queer aged 21-29)

There seems to be a wide variation in the perception of service quality according to the experiences of our respondents, from the initial contact and referral to getting Gender Reconstruction Surgery. Young people in particular seem to experience very confusing advice and support.

A mother of someone now in the age 20 - 29 age bracket in the South West of England told us that in 2011 when the young person was 15, that CAMHS (Child and Adolescent Mental Health Services) were “very unhelpful”. After seeing CAMHS 3 times with her child who was under 18 at the time, the mother then went to the GP

with a referral form to the Tavistock Institute that she had downloaded and completed herself. The GP was “happy to submit the form we had completed” and was rated neutrally on the friends and family scale in this instance. The young person went on to transition, using a Gender Identity Clinic, and then to have reconstructive surgery although at the time of writing it is too soon to say how satisfied they are with the outcome.

Another non binary young person said this:

*“Referred to Tavistock and Portman from [a London] CAMHS two weeks ago. Have yet to hear anything. When my friend was referred (from his GP) he waited four weeks to be seen, so expecting something like 5-7 weeks. In the meantime my CAMHS sessions have been moved further apart while we wait and when I get the appointment we will decide whether or not I keep going, or Tavi take over fully... When I first came out to CAMHS I asked for a referral, which they refused as “it’s the GPs job”. I then asked the GP who said “a referral has to come from CAMHS”. Went back to CAMHS (with a quote off the T&P website saying any medical professional can refer), the therapist told me she was leaving in a couple weeks and she didn’t have time, I should ask my GP again. After ending up back at CAMHS after an emergency referral to them a month or so later, my new therapist has agreed to refer me, and that has now been done. I will be giving a presentation to our local CAMHS clinicians in a couple of weeks to help teach them how to best support young trans people in their care.”*

(non binary person aged 17 or younger)

18 of our respondents were 18 or younger and reported similar confusion. The Parliamentary report that we have referred to elsewhere deals in more detail with children and young people, and their transition into adult services and we fully support their recommendations in this area.

## Relationships with the GP

A mixed picture...

*“There is a lot of bad information and a lot of good information... it’s a case of trawling away to find the right info. GP are very in the dark and need a lot more help and information. It felt like I was telling my GP what and how to do his job”*  
(woman aged 50 - 59)

How GPs carried out their role was crucial as for many it was the first point of contact: a fifth of all responses received to question 4 (see chart “Q4” in the appendix) cited their GP as a key information point. 67 people ticked this answer, although it was possible, however, to select more than 1 answer to this question, meaning the GP may not have been the sole information point.

Some found that the GP was happy to do some research, find out about the options and were “understanding” and “welcoming”, whereas another “didn’t have a clue”. That resulted in what appeared to be a wrong referral being made and further delay. One doctor got it completely wrong saying “it’s alright, it’s OK to be gay!!” (exclamation marks as per the contributor) whilst another had to “tell the GP the procedure, as he didn’t know”. More worryingly, people described some GPs as obstructive or unwilling to make appropriate referrals, or give treatment

particularly for hormones, which is looked at in more detail elsewhere in this report.

## Incorrect guidance on NHS Choices

Several people were wrongly referred to the local mental health team, resulting in delays for initial assessment. When we looked on NHS Choices we found why this may have been the case.

Commissioners and providers have told us that referral to the mental health team prior to the most recent specification (under the Interim Protocol) was a screening process intended to protect the patient from inappropriate treatment. Whilst many people may experience depression and anxiety or other symptoms as a result of gender identity issues, those symptoms may or may not be evidence of an underlying mental health problem that has a cause other than gender identity issues. Where there is another functional or organic mental health problem however, at that time it was felt necessary to conduct a “screening process” prior to further assessment and treatment.

People presenting with Gender Identity matters are not now considered to have a psychiatric problem purely as a result of these issues. The guidance and protocol has changed. We were told that the most recent specification has removed this step from the referral and treatment pathway. It is to be hoped that necessary referrals have been directly to the Gender Identity clinic since April 2013, when a full specialist assessment of the individual’s health needs takes place, although from our respondents, there doesn’t seem to be an overwhelming sense that the protocol is correctly referred to, let alone followed.

We found inconsistency about direct referral to the GIC was confirmed in the parliamentary report<sup>22</sup> thus:

*“ ... the GP believes local funding needs to be arranged or that a mental health assessment needs to be carried out, neither of which is true in England since April 2013.*

*In spite of the fact that gender dysphoria is no longer recognised as a mental health condition, many GPs will not refer to a GIC without assessment from a mental-health team (who are not in any way trained to understand or deal with gender dysphoria and gender issues).”*

The Interim protocol and flow chart states referral to GIC may come from a GP or other specialist clinic. The problem is that the NHS Choices transgender pages<sup>23</sup> have an available resource for people seeking help (and uninformed GPs?) that states:

*“People in need of help with psychological functioning and to make the transition of social status will require additional input from specialist mental health professionals with knowledge, training and experience in the treatment of Gender Dysphoria. This extra input may be available within the GIC or elsewhere.”<sup>24</sup>*

And:

*“Depending on local service arrangements, a mental health assessment may be required. If so, the GP should refer swiftly to the local Community Mental Health Team (CMHT) for assessment. The GP must then include the CMHT assessment in their referral to the Lead Clinician of the receiving gender service.”<sup>25</sup>*

This is no longer the case. NHS Choices states, in that completely out of date document,<sup>26</sup> that there will be new commissioning from April 2013 (page 1)- which happened on an interim basis - yet it is January 2016 and this information is not easily available in one of the most common online places the public and particularly GPs might go for trusted information. The Information Standard says information must be “clear, accurate, balanced, evidence-based and up-to-date”<sup>27</sup>.

## Statement from NHS England about NHS Choices

We contacted NHS England straight away, to help rectify the situation and were told by a senior commissioner with responsibilities for improving health services for transgender people that

*“The interim protocol that NHS England is currently using to commission gender identity services permits referrals directly from GPs.  
The document on the NHS Choices website, which reads otherwise, precedes the establishment of NHS England in 2013 and is incorrect.  
We will raise this with the NHS Choices team.”*

We thank NHS England for their swift action in resolving this and will be in communication with them to ensure this change is put into effect.

## Recommendation 2: Information

If independent sites are using the NHS information standard or have other reputable accreditation it may be helpful to clearly display this so that people know they are accessing good quality and trustworthy information from a publicly accountable source. The interim Gender Dysphoria Protocol<sup>28</sup> is in the public domain and on page 6 of that document you can view the Protocol Flow Chart. However, despite the presence of the NHS information standard quality mark, it is not referenced on NHS Choices. This should be rectified as soon as possible. Then, GPs and other service providers would know to make the protocol available to patients to help guide them. Perhaps GPs and other service providers would feel more confident and encouraged to give this information to patients seeking treatment.

## GPs: What works well

Half of the respondents to the question “How likely are you to recommend your GP to friends and family” said they were “likely” or extremely likely” with comments like:

*“Although this gp runs late, he cares about his patients, he treats me as a whole person and is understanding of my disabilities.”*  
(“mostly male” aged 30 - 39)

## Satisfied patients or grateful recipients?

There was a palpable mismatch between the friends and family ratings and what people told us in the qualitative information we received; a reasonable reading of these ratings may not be so much that people were satisfied, but this is an expression of gratitude that treatment and procedures were even accessed at all, let alone within NHS Constitution guidelines. Healthwatch England Chair Anna Bradley said in October 2013:

*“We all need to stop acting like grateful patients and care users and start to see ourselves as savvy consumers, insisting on our right to safe, dignified and high quality care.”<sup>29</sup>*

Our respondents appear to fully endorse that statement in the face of ignorance and in some cases, as the parliamentary report put it “out and out prejudice”.<sup>30</sup>

One person in their 20s, commenting on their experiences (initially referred to as “a straight forward case of gender dysphoria” by their first GP) with more than 1 GP...

*“Consulted with my GP in so much as they are the ones required to process the referral, and provide prescriptions. In the majority of cases they have not known the protocols, or at least not known the up to date ones, and have always had to clarify, despite me directing them to the NHS protocols on the matter...”*  
(man aged 18-20)

...the same man, having moved to a different town...

*“...currently under the care of [a surgery in the South West] who for the most part are fantastic, if only because they leave me to my own devices for most of it, and read up on it without a fight.”*

Professional views, opinions and approach varied from person to person, and some respondents had varied experiences to tell of having seen different health practitioners on the same matter.

*“Dr [B] ... did not bat an eyelid when I explained how young my daughter was when she transitioned, nor when I requested a referral to CAMHS. We have not need[ed]*

*to see her about this issue since, but I would anticipate that Dr B would be just as kind the next time we saw her. The head of surgery at the [anytown] practise was most unwelcoming however, saying that "neither he nor his staff had any experience nor interest in the area".*

(mother of female aged 17 or younger)

In talking about what worked well, many people said that even if their GP didn't know very much about transgenderism or gender dysphoria, a willingness to learn and do research on the subject, being non-judgemental and with an open mind, meant people felt supported and helped, which of course led to an improved experience of the service.

*"If your GP is sympathetic they can be useful as a referral agent to specialist GIs. However, if they are unsympathetic and/or know very little about it as an issue, it may not be particularly helpful. I think all GPs need to do some training on GI as more and more people are presenting with these issues."*

(parent of young man aged 19)

## GPs: What didn't work so well

What did not work very well was when the..

*"...GP surgery [was] not ... as hostile as some others, but neither have they been particularly helpful. One of the GPs caused me considerable embarrassment and inconvenience by misgendering me on paperwork several times (after all my official records had been already changed to reflect new name, title, and man gender, including my GP records. He was aware of these changes, but ignorance/transphobia left him unable to behave appropriately.) The practice initially refused to take over prescription of my hormone medication despite national guidelines and policy saying they should, because a legal loophole still allowed them to refuse and because they considered the medication and monitoring to be expensive. They eventually did agree to take over prescription after over a year of negotiation, and with the compromise of monitoring being carried out by a local endocrinologist instead."*

(non binary person aged 30-39)

Experiences like the above lead to enduring perceptions of prejudiced and inequitable service provision which is difficult to access.

Moreover, the parliamentary report found:

*"...it is clear from our inquiry that trans people encounter significant problems in using general NHS services due to the attitude of some clinicians and other staff when providing care for trans patients. This is attributable to lack of knowledge and understanding—and even in some cases to out-and-out prejudice.*

*...GPs in particular too often lack an understanding of: trans identities; the diagnosis of gender dysphoria; referral pathways into Gender Identity Services; and their own role in prescribing hormone treatment. And it is asserted that in some cases this leads to appropriate care not being provided."*<sup>31</sup>



## What can GPs do to improve?

The expectation by people of the GP is that they should be empathic, open and approachable, willing to learn and listen and address any gaps in knowledge. People seeking help who responded to our survey often felt that as long as the GP could:

- admit any gaps in professional knowledge without exercising judgement
- seek and accept information - not only from the NHS resources at their fingertips, but from the person sat in front of them (in many cases the patient will have researched their condition prior to consultation)
- use this information to further explain the referral and treatment process as much as possible

Then the individual concerned would most likely have a far more favourable experience.

Long waits outside the NHS Constitution limits for further treatment are unacceptable, but the quality of the role and personal approach of the GP during the wait can make things more bearable for some people.

*“My GP has been brilliant, completely supportive all the way through (2009 onwards). I went through the one local psych system via Manchester Royal Infirmary, again brilliant, I was referred to Charing Cross GIC, had a couple of minor niggles but nothing that couldn't be sorted out, overall they were very good to me. Finally and recently had my GRS [gender reconstruction surgery] at Charing Cross Hospital, again it was overall a very positive and pleasant experience with 1st class care and staff.”*

(woman aged 30 - 39)

Regarding other aspects of GP service provision, one person told us that:

*“My GP was supportive although she knew absolutely nothing she made an effort to be respectful. The surgery practice however were less helpful about my using a Mx title, and called me several times to query it / tell me I couldn't use it. They sent the records keeping department of the local NHS (don't know the name sorry) to call me as well. The lady was like “you don't have to say in between you can put the title of the gender you're transitioning to, which are you” to which I was “no, I AM nonbinary”. Eventually they let me use the Mx title. I don't know what gender they have written down for me though. Almost every time I call the surgery, the receptionist queries if my title is an error.”*

(non binary person aged 30 - 39)

## Patient centred practices

If services are to fit round patients, then this might be one example of how staff might need to be supported in their understanding of diverse groups and the needs of individuals: titles and prefixes do not always fit in pre-ordained boxes - do we even need pre-set Mr, Mrs, Miss, Ms etc? Are they in fact, lawful in this context? The cross- party parliamentary report for Transgender Equality...

*“calls for an introduction of the option to record gender as “X” in a passport as well as moving towards non-gendering official records - with gender only noted where it is relevant.”<sup>32</sup>*

## Referrals from the GP: waiting and travelling

People travelled hundreds of miles to clinics and surgery. Some had waited up to a year or even 2 for clinic appointments. Some people had appealed or complained as they were waiting even longer. Following the clinic there is another wait if surgery is needed - surgery waits are reported to be as long as 3 years on top of the wait to be assessed - with no communication or updates in between, resulting in 5 - 7 years at least before the process is anywhere near complete.

### Waiting...

One person said:

*“My GP referred me in February 2013. I got my first appointment on 9th July 2013. Although only five months, this was before the national clinic wait times were published by UKTRANSINFO and the Exeter Laurels clinic got swamped with hundreds of referrals. The poor buggers got ran into the ground trying to cope with the massive surge in demand for their help. They're still struggling to keep up even now. They simply don't have the resources to manage it all properly.”*  
(woman aged 40 - 49)

Another person said about the waiting times:

*“I then went back to my GP and explained that this feeling of 'putting my life on hold' was really impacting on me and making me unhappy. She agreed to prescribe me testosterone if we could get advice from an endocrinologist about monitoring my blood work. Once I had seen the endocrinologist, she prescribed me testosterone. This has had the biggest positive impact on my mental health and I no longer suffer from agoraphobia, and I now self-manage my depression and anxiety without medication through a combination of social support, meditation and diet and exercise.”*  
(non binary intersex person aged 21 - 29)

Some people have to go through long waiting times for the initial testosterone hormone treatment before having upper body surgery. There is then a further long period for lower body surgery.

Some have gone to other countries to have surgery. Some have surgery privately to “beat the system” and NHS waiting times. It seems from our findings, prior to 2010 some were going through the initial system in approximately 2 years, at present in 2015 it is apparent a longer wait ensues and people reported to us that it is getting longer.

From details given, a number of individuals feel the need for emotional and psychological support, because of the uncertainty experienced whilst waiting. Some feel they get the right signposting whilst others have experienced what they felt were inappropriate therapies.

## Recommendation 3: Communication

Communication from GP, clinic and surgical ward needs to be positive and proactive, not only about treatment and decision making, but to ensure individual information needs are met during referral and waiting times i.e. “how long is the list”, “how far am I down it?”

*“Had to go through 18 months of screening / local protocol just to get referral. Not great as I really needed to see a gender specialist earlier. Had to rely on Internet forums for support. Made me go to a primary care counsellor for 6 months who knew very little about transgender issues. Thank goodness I have friends who I came out to.”*

(woman aged 40 - 49)

## Travelling...

63 people specified the first part of the postcode and the Gender Identity Clinic or consultant that they visited. The furthest approximate distance of 1 round trip was 506 miles and the shortest round trip was approximately 14 miles. Only 6 of these people were offered advice or support about travel. Only 1 person specified that they had an HC2 travel certificate, which entitled them to support with travel, but even then an overnight stay would cost them 2 weeks income as they only had £52 per week coming in. They said that help for travel seems “deliberately obfuscated” and spent “three hours phoning around”. The clinic itself didn’t have a cash office to refund on the day for a 5 hour train journey, but claims can be processed by post. Nobody seemed aware this could happen.

The parliamentary report noted

*“the uneven geographical distribution of GICs, meaning that many people have to travel long distances in order to access treatment.”*<sup>33</sup>

Chart Q9(a) in the appendix gives a further breakdown of journey mileage.

Most people who answered our survey were on an income of under £19, 000. This represents another example of inequity, in that many people who may have been eligible for reimbursement of their travel costs, were not advised of this.

### Good practice tips: travel costs: Healthwatch Islington

Healthwatch Islington recently carried out a mystery shopping exercise<sup>34</sup> in their borough and as a result made the following recommendations with the GP practices and hospitals that they spoke to.

All hospitals should offer patients the option to claim travel costs by post  
GP reception staff in particular, need to be informed about the scheme and when it might apply to patients using their services  
Islington Clinical Commissioning Group should provide a briefing for all GP practices about the Healthcare Travel Costs Scheme

## Recommendation 4: Travel costs

In line with the recommendations from Healthwatch Islington, providers (GPs and clinics) need to be supported to ensure people are able to access the Healthcare Travel Costs Scheme<sup>35</sup>.

## Hair Reduction<sup>36</sup>

NHS England says in the interim Gender Dysphoria Protocol that...

*“The reduction of facial hair is seen as an essential part of gender reassignment for a transwoman to facilitate the period of living in the gender role that is congruent with the individual’s gender identity before genital reassignment surgery. The absence of facial hair is of psychological benefit and will produce a greater well-being for the patient as there should be little or no need to remove hair on a constant basis. It is recommended that facial hair removal should commence prior to social gender role transition, as the beard must grow to visible lengths to be removed.*

*A fixed number of [electrolysis] sessions (one site test and eight sessions), will be funded for facial hair reduction for trans-women”.*

Since 2013, hair removal in this context has been viewed as an essential part of the service.

15 people mentioned NHS funded electrolysis and said the funding for hair removal was not adequate to their needs.

There was a greater number who said they were fighting or had fought for funding (prior to 2013 hair removal was not routinely funded) or historically refused funding because of CCG/PCT restrictions. Many self-funded; those who did not have these resources have not had timely, or in some cases, any, treatment.

Individuals, who had hair removal, were given a set amount of treatments and then the funding was removed or ran out, further treatments were needed and they were unable to afford them. Some individuals were given the wrong treatment, such as being offered laser when “laser does not treat grey hair”. When the fixed

number of treatments was not enough, unwanted hair was not fully removed and grew back. Thus the desired result was not achieved, in that a funded treatment had not worked, and there was no psychologically beneficial “absence of hair”.

Many paid for treatment themselves and commented in this vein:

*“I have been referred for 25 hours of facial hair electrolysis, which is the number of hours the electrologist can support at her current hourly charge. After this is completed I will have to fund further facial electrolysis from my own resources. Since the actual number of hours needed is in the hundreds, NHS funding for this service is inadequate.”*

*(woman aged over 60)*

*“again a year long wait to get funding and then it was only for 8 electrolysis only sessions.... whats that going to do??? nothing. laser was forbidden even though its cheaper (overall) and faster... what a joke, I had to pay for laser myself. so much for it being a core treatment hey??”*

*(woman aged 30 - 39)*

## Recommendation 5: Hair reduction

If people have been unable to access NHS funded electrolysis or laser hair removal prior to 2013, this should be offered to them now in a timely and effective fashion, if it is a desired option at their stage of treatment. NHS England recommends that “facial hair removal should commence prior to social gender role transition, as the beard must grow to visible lengths to be removed.”<sup>37</sup> There are plenty of electrolysis providers, why are people having to wait for a year?

## Medication

*“Only now, nearly 2 years after I started hormone treatment, did the GIC give me a consent form and offer to provide hormones. There is a fear in the NHS about prescribing hormones, but why? ... more early hormone treatment is urgently needed.”*

*(woman aged 40 - 49)*

21 people “went private” during the wait, for hormones, consultation and psychiatric /psychological help. People were able to find the funds were motivated to do this from desperation, frustration and a lack of information in the meantime about what might be the most likely options available.

*“I was appalled at the 13 months' wait so went private to get approval for hormones, which I got very quickly and easily (app. £500). Unfortunately, to start the hormones I wanted to store my sperm first. I tried to on the NHS ..., but the people at the GP and the CCG managed to screw up the application and took 4 months to tell me it hadn't been accepted. I couldn't go through that again, it was*

*a really really low patch in my life waiting to hear back about that, so I went private for that too rather than reapply. That cost me travel ... from London twice as well as the service costs, £500 up front and around £150/year. I've also taken on the laser and electrolysis on my body, which is still ongoing and I've probably clocked up £10k on that so far."*

(woman aged 30 - 39)

*"Make GP appointment 2 weeks wait to see GP ... 6 further weeks wait for appointment with "Community Mental Health Team" (CMHT), which was dire (my "specialist" literally didn't know what "transgender" means) Apparently indefinite wait for GIC appointment—I was told I would wait about 12 months. It has been 12 months (since my CMHT referral) and I have had no contact from the GIC at all, though their website says they're overwhelmed with referrals. At that first appointment, I expect to be seen and "verified" as trans, and then given another appointment in six months during which I "might" get a HRT prescription; or, I might need to do "counselling" ("are you SURE you're trans?") --- In the meantime I've gotten private care: 2 weeks to see private psychologist (£250) 6 weeks of "mandatory counselling" at premium price (£150/session) 1 week for blood tests/results to come in 2 weeks for appointment with endocrinologist (£250), who hands me a box of testosterone and prescription in exchange for £65."*

(demi-boy, queer aged 21- 29)

21 people told us that they had accessed private healthcare for hormone treatment whilst waiting for consultancy. In general they thought the wait was inevitable due to funding or psychological reports.

Even though it was a tight line between timely and non-timely provision, most of the comments were negative in the content. The waiting time was the issue that caused the negativity, and many people who responded to this part of the survey self-medicated for the duration in unspecified (and possibly dangerous) ways.

*"I put myself on hormones as it was taking far to[o] long to get [t]o the clinic. the clinic times are horrendous. I only see my consultant twice a year. after transing for nearly five years I am still waiting for lower surgery. I got thick blood because of the testosterone & had been ill f[o]r along time but the clinic never found out till it was at dangerous levels & my heal[t]h was in danger".*

(man aged 40 - 49)

People repeatedly described feeling "desperate" for help. Some frustrated people among our respondents (maybe without the requisite financial resources to access private healthcare) had self-medicated, in a medically unsupervised environment. We have no way of telling how widespread that practice is.

In written evidence, NHS England conceded that there appeared to be a particular problem with some GPs who refused to prescribe [hormone therapy] to transgender and non-binary people, and to undertake assessments and investigations, even though they have been advised to do so by physicians in the specialist gender identity clinics.

*"NHS England has responded to this issue by publishing:*

*a Specialised Services Circular (SSC1417, March 2014) which is consistent with the General Medical Council's good practice guidance in Prescribing and Managing Medicines and Devices 2013. The circular clarifies that general practitioners are*



*responsible for the prescription of hormone therapy as recommended by the specialist gender identity clinics; for patient safety monitoring procedures; for provision of basic physical examinations within the usual competences of GPs; and for blood tests as recommended by the specialist gender identity clinics.”<sup>38</sup>*

Nevertheless somebody, having accessed private healthcare because of untimely service provision:

*“Was told by NHS Hormone specialist that they would not give advice to my GP to reduce risk for the medication I was on because they didn’t “trust” my private consultant who had given my diagnosis and delivered most of my care despite the specific Doctor being one of the registered specialists able to give support to a GRC application and having had NHS contracts previously.”*  
(woman aged 21 - 29)

Not everyone had a negative experience, and here somebody, after an initially bad experience with the GP, describes the difference that medication made to them.

*“I was offered hormones within 3 months. They have changed my life. Thank you NHS and I am happy for the first time in 50 + years.”*  
(woman aged 50 - 59).

## Recommendation 6: Access

|   |
|---|
| Waiting times and access to essential non-invasive procedures in the meantime, such as hair removal, and medication simply must be improved to reduce the anguish and risk that can be associated with such lengthy periods between assessment and surgery in particular. |
|---|

## Other treatment

Lots of people observed how difficult it had been to obtain funding for their treatment, particularly for hair removal, (either laser or electrolysis). A few people mentioned speech therapy in a similar vein. When treatment of this type was offered, there were often not enough sessions to complete the process.

Inequity of access to further treatment for facial feminisation which helped to stop transphobic attacks and increase self-esteem was a noticeable comment. Please see recommendation 6 above.

## Surgery

Most people who commented about surgery were very pleased with the results, saying that teams and clinics were “excellent” and “fantastic”. Sadly for some people the results were not so good and received mixed reviews. Some people felt bullied by staff. The person below had a very patchy experience. The resounding message being that in order to make an informed decision one needs to have empathic staff giving the right information from reliable and trusted sources.

*“Surgery referral was via the GIC, not my GP. The chest surgeon I was referred to was not knowledgeable about the procedure I wanted (and I was very clear to both the GIC and surgeon about). The GIC referred me to the surgeon knowing he did not usually carry out the procedure, but not bothering to do any further research as he was the 'usual' and most local option. The surgeon was too arrogant to admit his lack of knowledge, agreed to the procedure I requested, but carried out a completely different one instead. This led to a poor cosmetic result which has taken two surgeries so far and a further two in the future for a different surgeon to correct. On the other hand, the genital surgery team I was referred to are excellent and I would recommend them to anyone needing penile reconstructive surgery, especially trans people, but their administration and communication are very poor and unreliable due to insufficient admin and nursing staff. I would recommend a friend or family member ... to do their own research to find the best surgeons and procedures for them.”*

(man aged 30 - 39)

Chart Q14 in the appendix shows that 32 people who answered this question were likely or very likely to refer friends and family to this type of treatment compared to 14 who would not, with just over 1/5 of all respondents undecided. Again, are these “grateful patients” or satisfied consumers?

**Post-operative care** also had mixed reviews. People said they had been given a list of contacts and sources of help following procedures. Some people felt really well supported by their local clinic, GP or district nursing team and praised them very highly, whereas others felt angry, abandoned and alone following surgery. The reasons for this variation are not clear, however, advice and support are clearly important as for many people, surgery is not the final part of the journey.

## Conclusion

People had very mixed views about their experiences, that perhaps the outcome was what they wanted but the journey nevertheless was fraught with anxiety and frustration. Although waiting times do not seem to have improved, it seems as though younger people have a more favourable experience. This may be due to improved clinical practices and protocol, when compared to 30 years ago. It is still apparent that socially and culturally there is still a lot for medicine and in particular, general practice to learn about the treatment of transgendered and non-binary people. It is a great disservice to the progress that the NHS has made, not to have up to date information available to patients and practitioners re treatment pathways. A clear service model should be made available and actively promoted, for all who deal with or are in contact with trans and non binary people. Protocols and guidelines need clarification which in turn should be correctly reproduced on information sources, to help GPs and other health professionals to give the right information.

Can service providers affirm all these points, all of the time?

- Ability to identify which physician to go to with questions or concerns

- Positive communication with physician about treatment decision making
- Positive communication with ancillary staff
- Trust in the physician
- Trust in the health care system

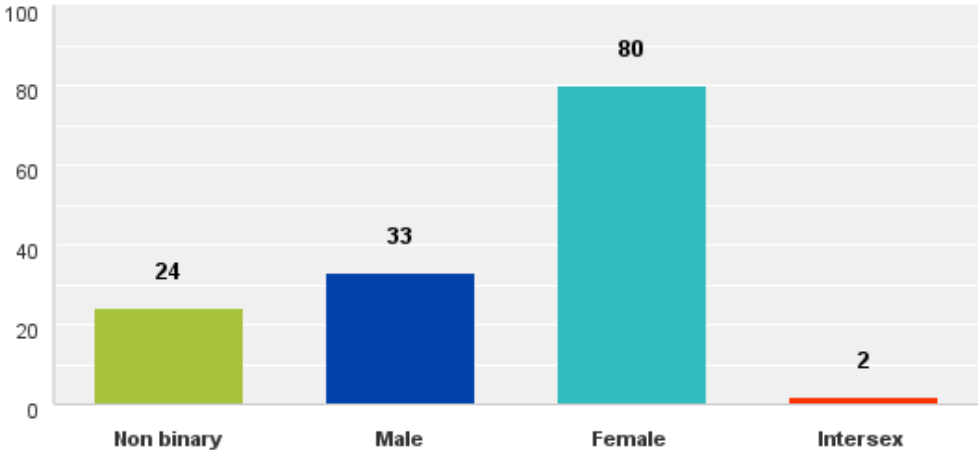
It appears not. The indication from many of our respondents is that they feel the system is not patient led and non-binary individuals in particular are slipping through, unable to get recognition from GPs or specialist clinicians.

Above all, people who are employed to look after those seeking help need to be supported and encouraged to understand their needs and act in a non discriminatory way. We welcome the call for a root and branch review. We will do our utmost to promote and support involvement in this area, and help champion equality in the NHS for all trans and non binary people.

# Appendix 1: Charts

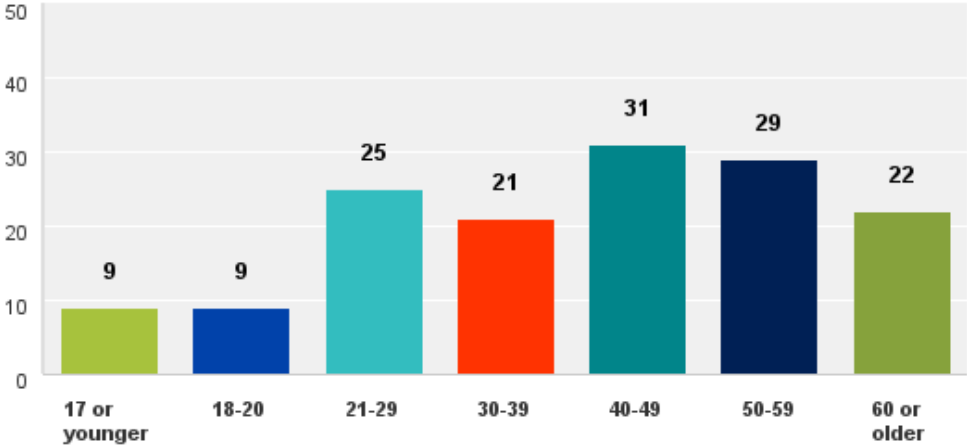
**Q1 Although you don't need to have accessed gender identity services to complete this survey, it will help us to know your gender status. Please indicate here how you define your gender.**

Answered: 139 Skipped: 10



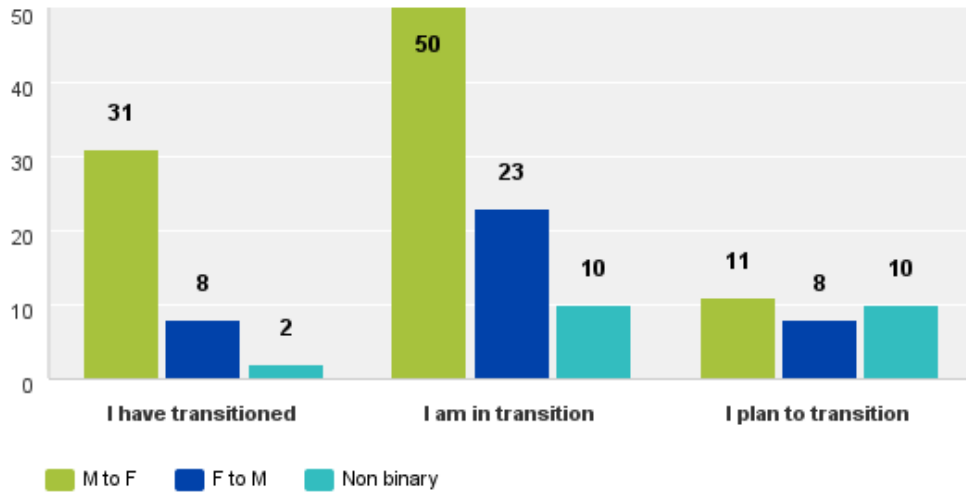
**Q2 What is your age?**

Answered: 146 Skipped: 3



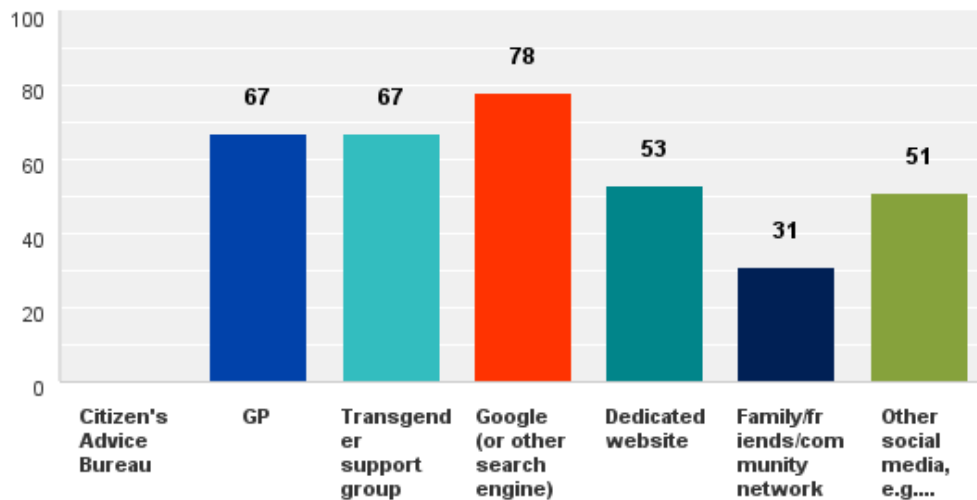
**Q3 Are you, or have you, transitioned from Male to Female/ Female to Male, or in any case do you identify as non binary or other definition? If you're not planning to transition, please skip this question.**

Answered: 140 Skipped: 9



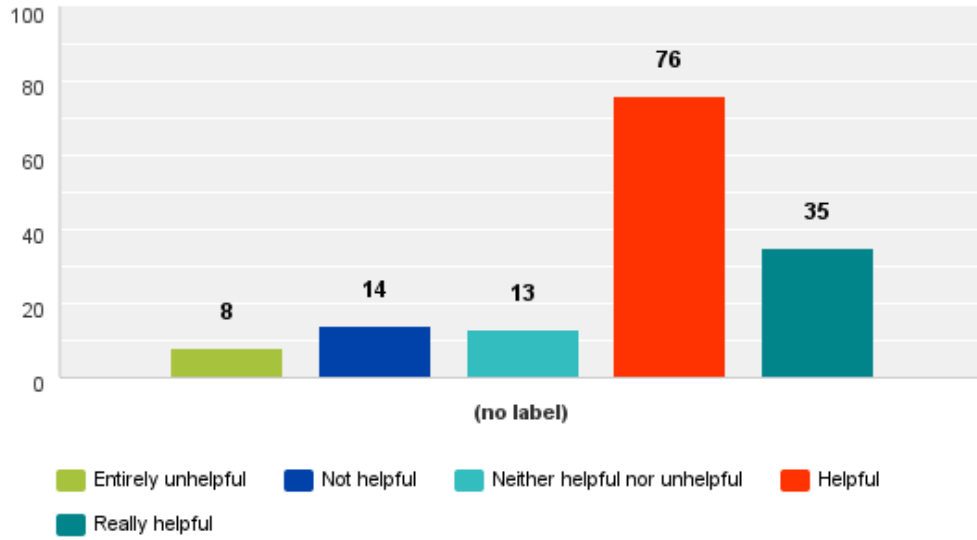
**Q4 When you began to seek advice and information about gender identity, where did you go for information? You can select more than one answer.**

Answered: 143 Skipped: 6



## Q5 How helpful was the information you found?

Answered: 146 Skipped: 3

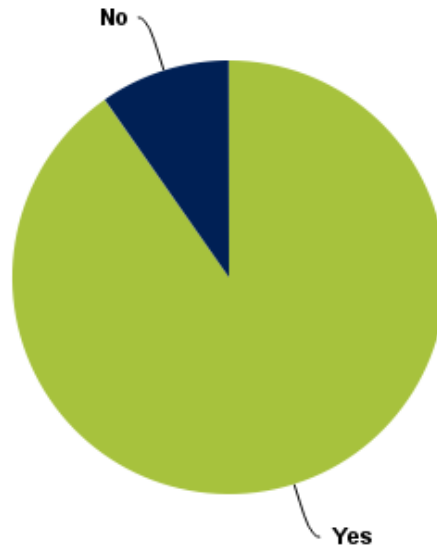




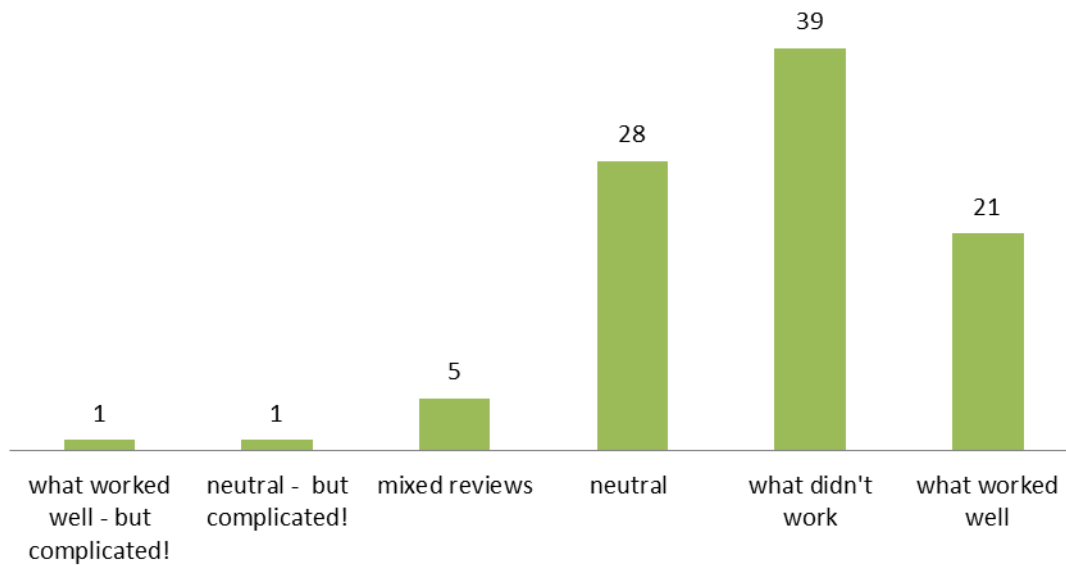
## Q6 If you need (or needed) gender identity services, have you consulted with your GP?

Answered: 144 Skipped: 5

### Chart A

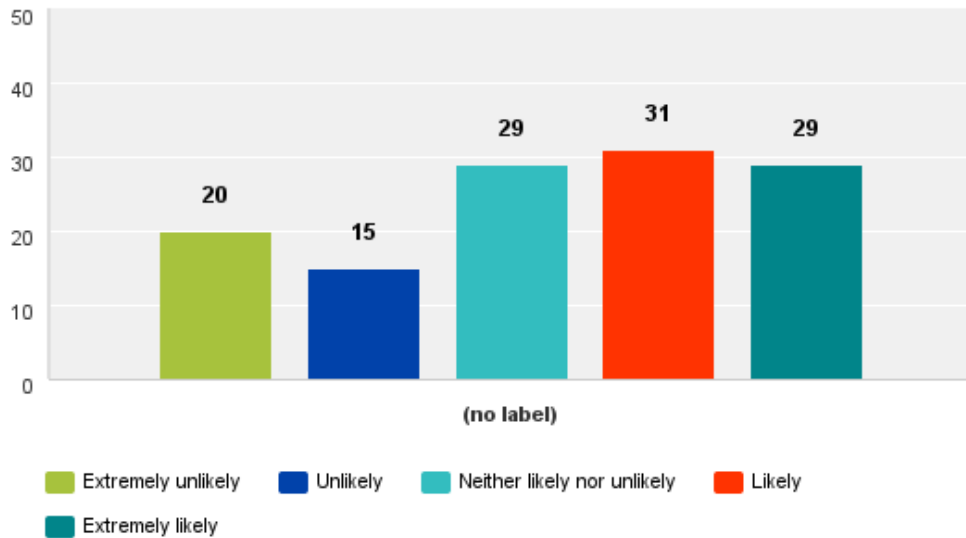


### GP Consultation Q6 Chart B: No of responses sorted by sentiment



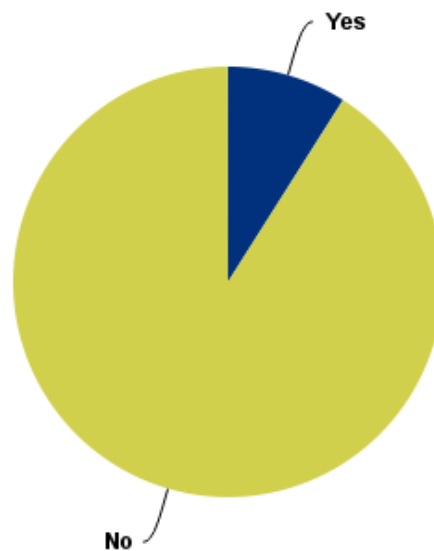
**Q7 Recommend to friends and family?How likely are you to recommend your GP surgery to friends and family if they needed similar care or treatment?**

Answered: 124 Skipped: 25



**Q9 Were you offered support and advice regarding costs of travel to treatment?**

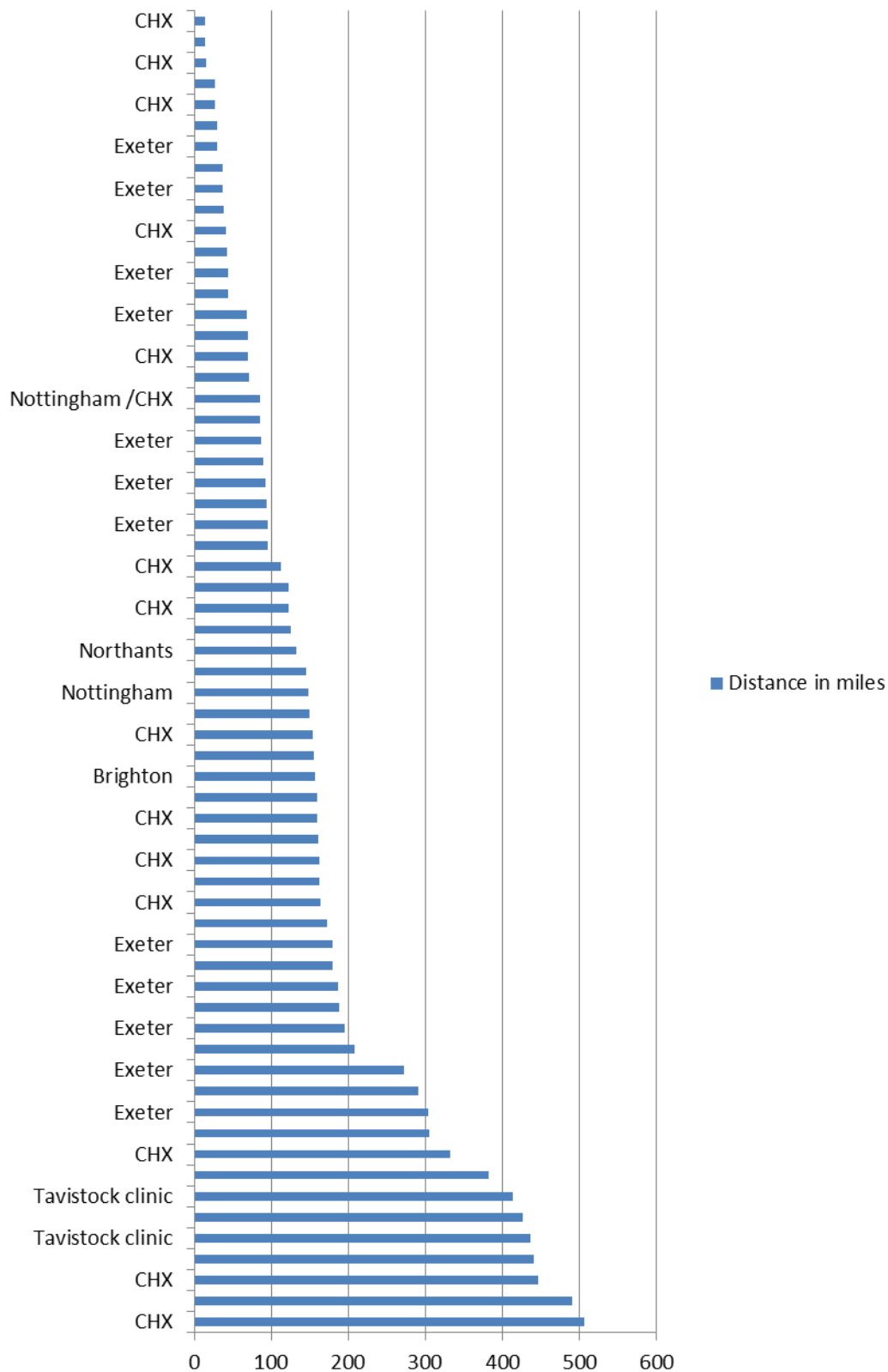
Answered: 111 Skipped: 38



Q9(a) distances from home to GIC

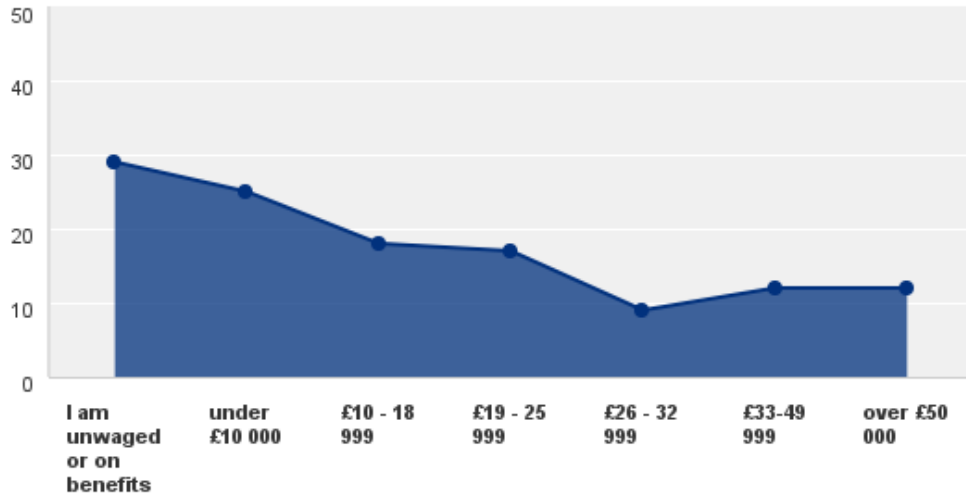
(1 round trip)

### Distance in miles



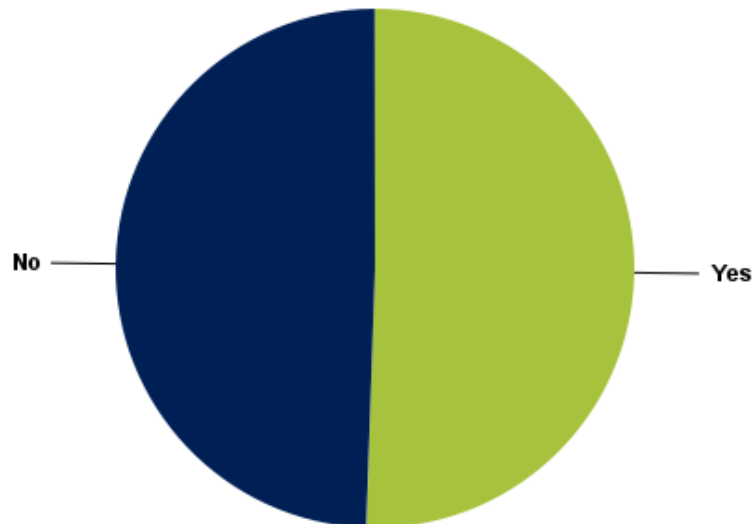
### Q11 Please tell us your yearly income level here.

Answered: 122 Skipped: 27



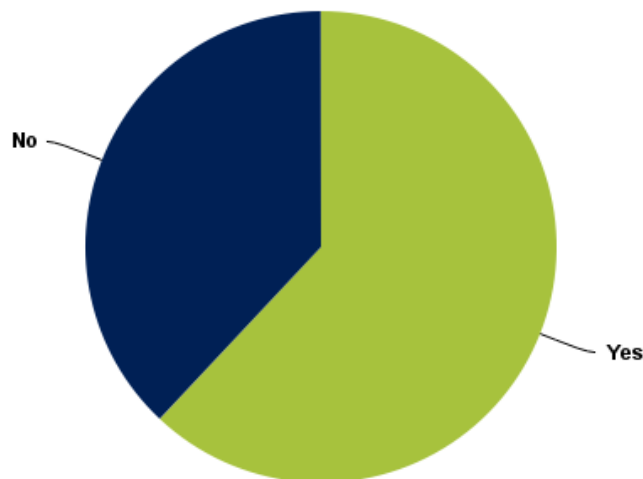
### Q12 If you've been prescribed medication, including hormone treatment for your condition, do you feel this was offered in a timely fashion?

Answered: 93 Skipped: 56



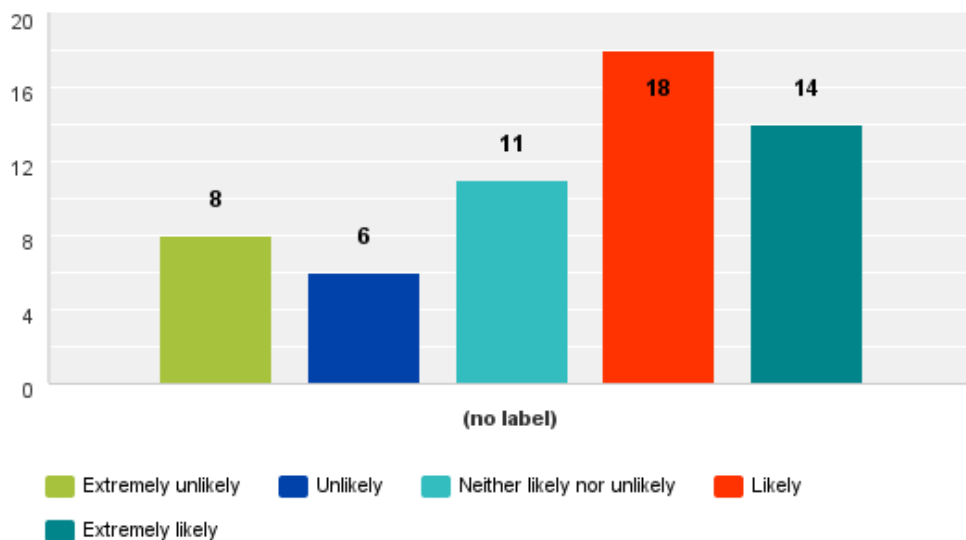
**Q13** If you needed treatment before accessing surgery (e.g. hair removal), did you encounter difficulties getting funding for this treatment? If this doesn't apply to you, please skip this question.

Answered: 50 Skipped: 99



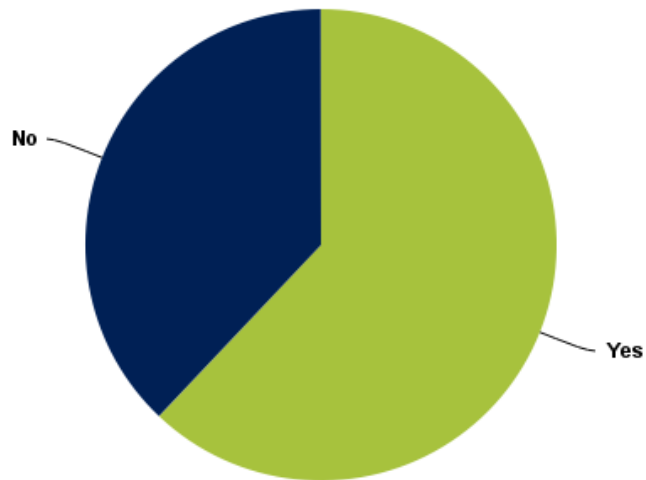
**Q14** If you've had further treatment or surgery (following a referral from your GP), how likely are you to recommend this service to a friend or family member requiring the same or similar treatment?

Answered: 57 Skipped: 92



**Q15 Regarding post-operative care, do you feel supported? Are you able to access continuing help and advice as an outpatient? If this doesn't apply to you, please skip this question.**

Answered: 29 Skipped: 120





## Appendix 2: Response from Devon Partnership Trust (Laurels Senior Management team)



### Response to Healthwatch England report into gender identity services

Devon Partnership NHS Trust is the provider of The West of England Specialist Gender Identify Clinic (also known as The Laurels) which is based in Exeter, Devon.

The service has gradually expanded since it was created in 1985 and has built a reputation for excellence and innovation in supporting people with a range of needs related to their gender. Feedback from people using the service is generally extremely positive.

Senior managers from The Laurels have met with representatives from Healthwatch Devon in recent months to discuss the survey that has been undertaken and to discuss how we can use the findings from the report to help inform the service we provide at The Laurels. It is useful to note that this survey was undertaken nationally as well as locally.

As the report rightly identifies, The Laurels has historically had one of the shortest waiting times of Gender Identity Clinics (GICs) in the country. Information regarding waiting times has regularly been published by support groups and other organisations on the internet since 2014. The fact that The Laurels' waiting times have been among the lowest in the country has contributed to an increase in referrals.

Each month, The Laurels receives in excess of 60 referrals. In response to a sustained increase in the referral rate to the service over recent years, a business case was submitted to expand the service in April 2015. This has resulted in an increase in staffing, in terms of both medical staff and therapists. However, as the report highlights, there is a national shortage of professionals who are experienced in working with individuals with gender identity issues and, as such, several of the new post holders have only recently commenced employment with the service.

Waits for initial assessment and medical appointments at The Laurels have increased significantly over the last 12 months and the average waiting time currently stands at 40 weeks from referral to initial assessment. While the team at The Laurels are understandably keen to reduce the length of time people have to wait wherever possible, the service still has one of the lowest average waiting times in the country. We are currently looking at the possibility of updating our website on a weekly basis to provide 'real time' information related to the waiting times for initial assessment, so we can provide an indication of how long it will be before we are able to offer appointments to people.

Individuals who require surgery face further delays in accessing these procedures. The

Laurels is working closely with its commissioners, NHS England, to address the issue of waiting times to access appropriate treatment and support.

The Laurels has undertaken a review of how it delivers services. This has been done with a view to streamlining the interventions it provides, focusing these interventions on the specific needs and goals of the individuals supported by the service and improving the efficiency of administrative systems and processes.

As The Laurels attracts referrals for individuals from all over the UK, we are acutely aware of the time and cost to people of having to attend appointments at our clinic in Exeter. We do provide information to people using the service on how to claim travel costs if they meet the eligibility criteria.

We will be reviewing the information we provide on our website to see if it can be more helpful for existing and prospective users of The Laurels. We have also looked at ways in which we can minimise travel costs and the time spent travelling. This work has included arranging medical and therapy appointments on the same day and providing the opportunity for people to have telephone or Skype consultations.

The service is also currently working with NHS England on a business case to provide a satellite clinic in Bristol, as we currently have a significant number of individuals who travel from the Bristol and Avon area to appointments in Devon.

As a service we look forward to continuing to work closely with stakeholders and interested parties, including Healthwatch Devon, with a view to developing a service which meets the needs of the individuals who are seeking our support.

**Senior Management Team**  
**The Laurels**  
**March 2016**

## Appendix 3: Response from South Devon and Torbay Clinical Commissioning Group



### Response to Gender Identity report by Healthwatch Devon: A report about the experiences, views and opinions of people using Gender Identity services in England

February 2016

#### Overview

South Devon and Torbay Clinical Commissioning Group does not commission or provide gender identity services, and it would be helpful to make this clear in the report. However, we are broadly supportive of Healthwatch Devon's awareness raising and recommendations; we have also raised this issue with NHS England ourselves, following feedback we have received about services. There are many parallels to the recent House of Commons Women and Equalities Committee report into transgender equality: <http://www.bbc.co.uk/news/uk-35302670>

#### Prescribing issues

The gender identity service is a specialist one, commissioned by NHS England so it is difficult to comment in any detail, apart from where there are links with GPs. As an organisation with a GP membership, we are aware of the difficulties around prescribing (sections 51, 104, 144-148). It is not uncommon for GPs to be in an invidious position with expectations to prescribe drugs that are not licensed for this management, when they don't have the specialist knowledge necessary to prescribe.

We acknowledge that it is an area where there is unacceptable variation in the levels of compassion with which this group is cared for (sections 87, 103, 106-118). Being a relatively rare condition, it is likely that there is also probably lack of knowledge within primary care (57.2), but that is no different from any other condition with a similar prevalence. We would not expect general practitioners to have detailed knowledge on this subject, although it is certainly something we can support with awareness raising.

#### Transport

Section 128-134 and recommendation 4 is about transport funding for patients. It is important to emphasise that help with the cost of transport exists for any patient who meets the government's criteria for the Healthcare Travel Costs Scheme for which more information is available on our [website](#) and we have distributed leaflets.

- 
- <sup>1</sup> Interim NHS England Gender Dysphoria Protocol and Service Guideline 2013/14 p5
- <sup>2</sup> <http://www.nhs.uk/public-i.tv/core/portal/genderid-symposium>
- <sup>3</sup> <https://www.england.nhs.uk/ourwork/patients/public-voice/identity/>
- <sup>4</sup> <http://www.healthwatchdevon.co.uk/gender-identity-services-your-voice-counts-torbay-plymouth-and-devon-healthwatch-working-together/>
- <sup>5</sup> [http://www.publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/39008.htm#\\_idTextAnchor261](http://www.publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/39008.htm#_idTextAnchor261)
- <sup>6</sup> <http://www.theguardian.com/society/2016/jan/14/transgender-people-being-let-down-by-nhs-say-mps>
- <sup>7</sup> [http://www.publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/39008.htm#\\_idTextAnchor261](http://www.publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/39008.htm#_idTextAnchor261)
- <sup>8</sup> <https://www.advisory.com/research/oncology-roundtable/oncology-rounds/2012/05/what-factors-influence-patients-perceptions-of-care-quality>
- <sup>9</sup> <http://jco.ascopubs.org/content/early/2012/04/09/JCO.2011.38.7605>
- <sup>10</sup> <https://www.england.nhs.uk/2016/02/will-huxter-7/>
- <sup>11</sup> <http://www.healthwatchdevon.co.uk/gender-identity-services-your-voice-counts-torbay-plymouth-and-devon-healthwatch-working-together/>
- <sup>12</sup> Interim NHS England Gender Dysphoria Protocol and Guideline 2013/14 p 24
- <sup>13</sup> <http://www.nhs.uk/Livewell/Transhealth/Pages/Transhealthhome.aspx>
- <sup>14</sup> <https://www.england.nhs.uk/2013/10/gender-protocol/>
- <sup>15</sup> <http://www.nhs.uk/NHSEngland/Healthcosts/Pages/Travelcosts.aspx>
- <sup>16</sup> The Transgender Umbrella (Cambridge University Student Union definition)  
<http://www.lgbt.cusu.cam.ac.uk/resources/trans/transgenderism/>
- <sup>17</sup> Roizen M.F. and Oz M.C. and Joint Commission Resources Simon and Schuster New York 2006
- <sup>18</sup> <https://www.advisory.com/research/oncology-roundtable/oncology-rounds/2012/05/what-factors-influence-patients-perceptions-of-care-quality>
- <sup>19</sup> Advisory.com ibid
- <sup>20</sup> [https://www.youtube.com/watch?v=HYwZxheW\\_Sg](https://www.youtube.com/watch?v=HYwZxheW_Sg) Healthwatch Hampshire video
- <sup>21</sup> <http://www.healthwatchdevon.co.uk/made-of-rainbows-film2/> Healthwatch Devon video
- <sup>22</sup> <http://www.publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/390.pdf> para 157
- <sup>23</sup> <http://www.nhs.uk/Livewell/Transhealth/Documents/gender-dysphoria-guide-for-gps-and-other-health-care-staff.pdf>
- <sup>24</sup> <http://www.nhs.uk/Livewell/Transhealth/Documents/gender-dysphoria-guide-for-gps-and-other-health-care-staff.pdf> page 4
- <sup>25</sup> <http://www.nhs.uk/Livewell/Transhealth/Documents/gender-dysphoria-guide-for-gps-and-other-health-care-staff.pdf> page 7

- 
- <sup>26</sup> <http://www.nhs.uk/Livewell/Transhealth/Documents/gender-dysphoria-guide-for-gps-and-other-health-care-staff.pdf> page 1
- <sup>27</sup> <https://www.england.nhs.uk/tis/about/the-info-standard/>
- <sup>28</sup> <https://www.england.nhs.uk/2013/10/gender-protocol/>
- <sup>29</sup> <http://www.bbc.co.uk/news/health-24442895>
- <sup>30</sup> [http://www.publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/39008.htm#\\_idT\\_extAnchor261](http://www.publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/39008.htm#_idT_extAnchor261) para 182
- <sup>31</sup> [http://www.publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/39008.htm#\\_idT\\_extAnchor261](http://www.publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/39008.htm#_idT_extAnchor261) para 182
- <sup>32</sup> <http://www.theguardian.com/society/2016/jan/14/transgender-people-being-let-down-by-nhs-say-mps>
- <sup>33</sup> [http://www.publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/39008.htm#\\_idT\\_extAnchor261](http://www.publications.parliament.uk/pa/cm201516/cmselect/cmwomeq/390/39008.htm#_idT_extAnchor261) para 218
- <sup>34</sup> <http://www.healthwatch.co.uk/news/healthwatch-islington-helps-people-claim-back-healthcare-travel-costs>
- <sup>35</sup> <http://www.nhs.uk/NHSEngland/Healthcosts/Pages/Travelcosts.aspx>
- <sup>36</sup> Interim NHS England Gender Dysphoria Protocol and Guideline 2013/14 p 22
- <sup>37</sup> Interim NHS England Gender Dysphoria Protocol and Guideline 2013/14 p 22
- <sup>38</sup> <http://shsc.nhs.uk/wp-content/uploads/2014/08/NHS-England-Specialised-Services-Circular.pdf>